

NORTHEASTERN UNIVERSITY  
**LAW REVIEW**

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**SYMPOSIUM**  
**In Honor of Hope Lewis**

*International Law, Local Justice:  
Human Rights Transformed*

**Northeastern University School of Law**  
**Friday, November 17, 2017**

Introduction

*Margaret B. Kwoka\**

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\* Associate Professor of Law, University of Denver. The author holds a J.D. from Northeastern University School of Law granted in 2007.

It is a great privilege to introduce this symposium issue honoring the life and work of Professor Hope Lewis, whose tenure on the faculty at Northeastern University School of Law lasted nearly twenty-five years. As this volume will demonstrate, Professor Lewis was anything but unidimensional. She was an activist and an academic; a teacher and a scholar; a witness to injustice and a powerful voice for change. Likewise, her focus within the field of international human rights law was anything but traditional. While the field had been dominated by inquiry into the proper relationship between a state and its people as defined by treaty obligations and aspirations for international enforcement, Professor Lewis shifted the conversation toward the much more complex relationship between human rights and transnational, global economic systems. Her work was nothing short of pioneering, and this volume is itself a testament to Professor Lewis's professional legacy, breadth of interests, and powerful intellect.

But before I turn to the body of work that follows, I would be remiss if I did not comment on the impact Hope had on me and many others of her students, colleagues, and friends. I first met Hope when, in my second year of law school, I took her international human rights seminar. Hope was the kind of teacher I still strive to be to this day: absolutely brilliant, constantly pushing us, but never unkind. She had a way of asking a question that at once exposed the flaws in an argument and paved the way to improve it. She would loop in a comment a student had made a half an hour before, showcasing students' thinking and going out of her way to encourage us to be the very best versions of ourselves.

The seminar required a final research paper, and I chose a topic based on my then-recent experiences living in West Africa: international human rights law and the practice of female genital mutilation. When I began my research, to my great chagrin, I discovered Hope had written the seminal articles deftly unpacking this topic, which lies at the complicated intersection of cultural heritage, gendered violence, and self-determination.<sup>1</sup> I broached with her that perhaps my topic was not the best one for me to explore as a second-year law student, given that her own insights were far more advanced than mine would be, and published in a journal at Harvard no less! But typical of Hope's unwavering belief in her students, she

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1 See, e.g., Hope Lewis, *Between Irua and "Female Genital Mutilation": Feminist Human Rights Discourse and the Cultural Divide*, 8 HARV. HUM. RTS. J. 1 (1995).

told me how much work there was still to do, and how she thought I could make a contribution. I did write that paper, and when I was done, Hope was ecstatic. She helped me turn that paper into my first published work,<sup>2</sup> and then she was the very first person to cite my work in her own.<sup>3</sup>

Her belief in my nascent scholarship was directly responsible for me finding my courage to pursue an academic career. When I talked to my various faculty mentors about a path to the professoriate, I was grateful for the many instances in which they honestly—one might say sometimes brutally honestly—described to me a difficult and uncertain road that lay ahead. What Hope did, however, was endlessly cheerlead my dreams. It may have been the thing that got me here.

Now in my seventh year in the academy, I have also learned of Hope's incredible reach and influence within the progressive legal academic community. When I sat on the board of the Society of American Law Teachers, we honored Hope with the M. Shanara Gilbert Human Rights Award.<sup>4</sup> When considering the nomination materials, I learned even more about her lifelong commitment to international human rights work, particularly battling for the recognition of economic, cultural, and social rights, in addition to political and civil rights.<sup>5</sup> Prior to her career in academia, Professor Lewis was a key player in the Free South Africa Movement, working with TransAfrica Forum.<sup>6</sup> Her scholarship and activism while in the academy similarly sought to change legal norms around some of the most pressing social issues. She worked to secure rights for Haitian refugees<sup>7</sup> and called attention to the role of multinational

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2 See Margaret B. Kwoka, *Female Genital Surgeries: Rethinking the Role of International Human Rights Law*, 3 HUM. RTS. L. COMMENT, 2008, at 1.

3 See Hope Lewis, *Female Genital Mutilation and Female Genital Cutting*, in 2 ENCYCLOPEDIA OF HUMAN RIGHTS 200, 211–12 (David P. Forsythe ed., 2009).

4 Soc'y of Am. Law Teachers, *SALT Recognizes Honorees at 2015 Annual Dinner in Washington, DC*, SALT (July 14, 2014), <https://www.saltlaw.org/recognized-at-upcoming-annual-dinner-in-washington-d-c-january-4-2015/>.

5 See, e.g., JEANNE M. WOODS & HOPE LEWIS, *HUMAN RIGHTS AND THE GLOBAL MARKETPLACE: ECONOMIC, SOCIAL, AND CULTURAL DIMENSIONS* (2005).

6 Diane Marie Amann, *Go 'Grrl! ABA honors Hope Lewis*, INTLAWGRRLS (Dec. 13, 2011, 6:00 AM), <http://www.intlawgrrls.com/2011/12/go-grrl-aba-honors-hope-lewis.html>.

7 See, e.g., IMMIGRATION WORKING GROUP, U.S. HUMAN RIGHTS NETWORK, *RIGHTS OF IMMIGRANTS IN AND MIGRANTS TO THE UNITED STATES*

corporations in human rights crises in the Caribbean.<sup>8</sup> She did not keep her words on the page, but rather translated them into action. Her influence was felt far beyond the walls of her home institution and the people who passed through it. When Hope took the stage at the dinner where she received the Human Rights Award, I saw a sea of faces in the audience whose lives and careers had been touched by Hope.

As you read the pages of this volume, I think you will see a glimpse of the impact of Professor Lewis's body of work. These articles are, as Hope's work was, truly intersectional in their approach to identity, inequality, and social justice. They operationalize her struggle to expand our understanding of human rights. They model engagement with the intersectional identities of many marginalized communities. And they pay personal tribute to the impact Hope has made as a scholar, colleague, and friend.

Professor Berta Esperanza Hernández-Truyol uses the frame of dignity to examine the quest to expand the understanding and experience of human rights to include economic, social and cultural rights.<sup>9</sup> She explores the role of dignity in both domestic and international law contexts, and deftly unpacks how a liberal democratic frame can sometimes thwart the realization of expansive human rights.

In this same vein, Neda Saghafi acts on Professor Lewis's call for an expansive vision of human rights, one that recognizes local injustices using an international framework.<sup>10</sup> She documents how low-income women of color are disproportionately impacted by the existence of violent, hegemonic masculinity in police culture. In the context of other problematic policing practices, such as discriminatory stop-and-frisk, increased police militarization, and

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3–5 (2007), [http://www.theadvocatesforhumanrights.org/uploads/us\\_cerd\\_rights\\_of\\_immigrants\\_migrants\\_july\\_2007.pdf](http://www.theadvocatesforhumanrights.org/uploads/us_cerd_rights_of_immigrants_migrants_july_2007.pdf) (to which Hope Lewis was a contributor).

8 See, e.g., Hope Lewis, *Lionheart Gals Facing the Dragon: The Human Rights of Inter/National Black Women in the United States*, 76 OR. L. REV. 567, 613, 616 (1997); Hope Lewis, "Culturing" Survival: Afro-Caribbean Migrant Culture and the Human Rights of Women Under Globalization, 93 AM. SOC'Y INT'L L. PROC. 374 (1999).

9 As Hope Lewis pioneered. See, e.g., WOODS & LEWIS, *supra* note 5.

10 See, e.g., Hope Lewis, *Race, Class, and Katrina: Human Rights and (Un)Natural Disaster*, in ENVIRONMENTAL JUSTICE IN THE NEW MILLENNIUM: GLOBAL PERSPECTIVES ON RACE, ETHNICITY, AND HUMAN RIGHTS 233, 238–43 (Filomina Chioma Steady ed., 2009) (documenting human rights violations in the context of Hurricane Katrina).



mass incarceration, the experience of low-income women of color interacting with the police is amplified. The article seeks to use an international human rights framework to expose the power scheme in this domestic context. It is a powerful—and classic Professor Lewis—cross-context analysis.

Professor Brook Baker's work is a tribute to Professor Lewis's commitment to concrete change,<sup>11</sup> insofar as it brings what can be a lofty topic—access to medicines—down to the ground level. Professor Baker uses a human rights framework to analyze the licensing agreements that most effectively provide access to affordable medicines for people living with HIV and Hepatitis C. Nothing would have energized Professor Lewis more than a proposal for a concrete step to move toward an inclusive vision of human rights.

Intersectionality is also a prominent feature of the scholarship in this volume. Professor Elizabeth Kanter and Carla Villarreal López examine the complex relationship between domestic law and international human rights law as it plays out on the ground in Perú for women and girls with disabilities. They document how domestic law can “deprive women of their legal capacity” and thus prevent them from realizing the rights they hold under both domestic and international law. Indeed, this work is directly in the vein of Professor Lewis's own work on violence against women and girls with disabilities as it is experienced in particular countries.<sup>12</sup>

Similarly, Paul Harpur and Michael Ashley Stein look at disability from a human rights perspective, focusing on barriers to higher education for students with disabilities. This piece not only analyzes the governing legal frameworks, but also “interweaves salient narratives by stakeholders . . . to ensure their voices are heard and their concerns acknowledged.” Professor Lewis's own work often exhibited the same commitments to narrative as a powerful agent of understanding and change.<sup>13</sup>

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11 See, e.g., PROGRAM ON HUMAN RIGHTS AND THE GLOB. ECON., NE. UNIV. SCH. OF LAW, THE BOSTON PRINCIPLES ON THE ECONOMIC, SOCIAL, AND CULTURAL RIGHTS OF NONCITIZENS (2011) (enumerating a comprehensive, concrete set of principles for implementing an expansive vision of human rights); *Hope Lewis*, NE. U. SCH. L., <https://www.northeastern.edu/law/faculty/directory/lewis.html> (last visited Mar. 15, 2018) (listing Hope as a co-drafter and compiler of the Boston Principles).

12 See, e.g., STEPHANIE ORTOLEVA & HOPE LEWIS, FORGOTTEN SISTERS – A REPORT ON VIOLENCE AGAINST WOMEN WITH DISABILITIES (2012).

13 See, e.g., Hope Lewis, *Lionheart Gals Facing the Dragon: The Human Rights of Inter/*

Contributors to this volume have also reminded us of Hope's personal impact on those of us fortunate enough to have known her. For example, in Professor Ibrahim Gassama's intellectual relationship with Professor Lewis, he seems to have found his counterpoint. Professor Gassama's self-described cynicism was met head on by Professor Lewis's "relentless pursuit of meaning and her enduring commitment to lighting paths forward through the darkness." As he describes: "Hope protected and defended her right, and the right of the people she was part of and wrote about, to imagine a better world even under the most trying and absurd circumstances." Nothing seems more true to anyone who knew her.

Similarly, Jeribu Hill describes the personal connection she made with Professor Lewis in the context of a professional engagement. Indeed, Ms. Hill sees her own interactions with Professor Lewis as a model of Lewis's commitment to "amplif[y] women's voices and celebrate[] their scholarly and visionary contributions to revolutionary feminist theory and practice." Ms. Hill cogently describes how Professor Lewis's work recognizes the "full range of injustices" experienced particularly by Black women. You will see the impact of Professor Lewis's work when you read Ms. Hill's powerful words.

I hope you enjoy reading these marvelous tributes to Hope as much as I have. I will conclude my own reflections by noting that Hope not only went out of her way to boost my career at every stage, but her example inspired me to see the critical role of academics in linking theory, policy, social change, and education. I work to live up to Hope's example, and to honor her legacy. Because of Hope, and other members of the Northeastern faculty to whom I owe so much, I know what a difference a teacher can make. It has been a privilege to learn more about Hope's impact by participating in this symposium, and I thank the organizers and participants for the chance to remember Hope together.

\* \* \*

## In Praise of Hope Lewis—Thank You Symposium in Honor of Hope Lewis

*Jaribu Hill\**

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\* Jaribu Hill is a Civil and Human Rights Attorney in Mississippi. She received her B.A. from Central State University in Ohio and earned her J.D. from CUNY School of Law, where she was the first alumni to win the school's Dean's Medal. Hill is also admitted to the U.S. Supreme Court and serves as a Special Master in Washington County's Chancery Court, and is a former Municipal Judge for the City of Hollandale, Mississippi. She is also the Founder and Executive Director of the Mississippi Workers' Center for Human Rights. Through her organization, Attorney Hill has provided legal representation and advocacy for hundreds of workers in Mississippi, and her efforts have led to the adoption of "Zero Tolerance Against Hate" policies being implemented in workplaces across Mississippi. Hill is the recipient of the coveted "Gloria" Award, named for Gloria Steinem, and is a Skadden Fellow and the recipient of the R. Jess Brown Award, which is the highest award given to a Mississippi Lawyer by the Magnolia Bar Association. Hill frequently speaks and writes on international human rights issues. Her articles have been published in law reviews and journals, including Southern University Law Review, Columbia University Black Law Journal, and Columbia University Law Review. She is the author of *Knowledge is Power—A Know Your Rights Manual* and co-author of *The Black College Guide*. Hill has appeared on various TV and Radio programs, including TV One's acclaimed series: *Murder in Black and White*. Attorney Hill serves on Mississippi's Access to Justice Commission. Learn more about Hill's work. Visit her Blog (Back in the Day is Today) on Word Press.com. Hill is also the host of "Talking Rights With Jaribu", a weekly radio program on WDSV 91.9 FM.

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## I. Tribute

*Sister praise for one who pushed past the superficial darkness  
to walk in her light—past the limitations of retina and  
skin—of physical challenges—  
of slow motion steps  
To be  
To be  
To be  
Hope—Unsung Super Hero  
Where’s the cape to beat back the hard times—pain?  
Where are the wings and golden lasso?  
The secret caves—the refuge for those who  
Scale tall mountains of backlash and pushback  
Where’s the crown--the magic wand—juju beads  
Where’s what you need, when you need it?<sup>1</sup>*

In praise of Hope Lewis, who wanted this knowledge we are privileged to hold to have deep-water depth—to boldly challenge the unworkable order of things; to create new models for critique and criticism. Hope, I know you are listening, so THANK YOU!

My Hope experience began with a phone call from this quiet giant. We big-mouthed people often confuse voice volume with depth and assume the quiet voice is a weaker one. These assumptions keep us from knowing what real strength is; what real courage is and what real sacrifice is. Hope was calling to invite me to be the 12th Annual Valerie Gordon Lecturer at Northeastern University School of Law. It was a request I would not refuse. We formed our bond on that call—sharing stories about our work as lawyers in the human rights movement. We talked about the need to make the scholarship more relevant to those who suffer daily human rights abuses where they work. We talked about the need for an educational program that would provide the tools needed to decolonize and demystify the language—rejecting the stale and often class-biased legalese. We grappled with how to bring the human rights framework to those who needed it the most.

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<sup>1</sup> Jaribu Hill, original unpublished work on file with the author written on Nov. 11, 2017.

My Valerie Gordon Lecture—titled “Back in the Day is Today,” took root on that call from Hope. I knew why I was called and the message I had to bring. It was a message guided by Hope Lewis and all of her teachers, mothers, mentors, sisters and warriors in the law. It was what renowned poet, Gwendolyn Brooks declared: “What I’m fighting for now in my work for an *expression* relevant to all manner of blacks, poems I could take into a tavern, into the street, into the halls of a housing project.”<sup>2</sup>

Hope knew about the traveling work; the thinking work and the doing work. Hers was a commitment to a living, walking, and breathing scholarship that would help the sufferers of some of the most severe human rights abuses develop strategies for change, and raise worker consciousness about the systems of domination and control. Professor Lewis actively engaged her students and colleagues in the necessary task of demystifying the contents contained in the bound volumes of human rights treaties, conventions and declarations, including UDHR<sup>3</sup> and CERD.<sup>4</sup>

Hope Lewis’ approach to human rights scholarship and advocacy reinforced the importance of developing strategies that connect theory with practice. Lewis’ intentional departure from educational and organizing models that separate theory from practice made her a leader in the field. Her brand of functional scholarship helped to shake the walls of the gated towers to force inclusion of new, and in some ways, nontraditional theoretical and ideological frames. She understood the importance of intentionally and actively recruiting those historically excluded from the academy’s roster of scholars.<sup>5</sup> Professor Lewis was steeled in both theory and practice. She invited her students to look beyond case studies offered in law school textbooks and exposed them to real life experiences of those who daily suffer human rights abuses in the U.S. and across the globe. Hope paid close attention to current events and recounted the

2 GWENDOLYN BROOKS, *CONVERSATIONS WITH GWENDOLYN BROOKS* 107 (Gloria Wade Gayles ed., 2003).

3 G.A. Res. 217 (III) A, Universal Declaration of Human Rights (Dec. 10, 1948).

4 G.A. Res. 2106 (XX), International Convention on the Elimination of All Forms of Racial Discrimination (Jan. 4, 1969).

5 Many of the Lecturers in the Valerie Gordon Lecture Series were activist scholars routinely excluded from the “academy’s” roster. For a list of past scholars invited to speak at the Valerie Gordon Lecture Series, see generally, *Valerie Gordon Human Rights Lecture*, NORTHEASTERN UNIVERSITY SCHOOL OF LAW <http://www.northeastern.edu/law/academics/institutes/cpiac/programs/gordon.html> (last visited June 20, 2018).

realities of transnational exploitation experienced by Black women in the Americas and the Caribbean.<sup>6</sup> Like the “dragons” faced by Hope Lewis’ *Lionheart Gals*, the dragons faced by these women appear to be insurmountable; however, each story reveals their strong resolve and determination to press forward in spite of the odds.<sup>7</sup>

Other human rights defenders and feminist scholars agreed with Lewis through their works. Reading the words of these celebrated authors and thinkers, one immediately observes a common thread running through these works. They are lyrical accounts of slow moving, broad-backed, stubborn-boned Black women that must be told. Their stories of survival and triumph must be shared with all who dare to go against the grain.<sup>8</sup> Hope Lewis brought these women

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6 See Hope Lewis, *Global Intersections: Critical Race Feminist Human Rights and Inter/national Black Women*, 50 ME. L. REV. 309, 312–18, 321–22 (1998), for a discussion on the impact of European colonialism and imperialism on the ability of these women to avoid what Lewis calls cultural dislocations, and how these women, victims of race, class and gender oppression are afforded few options and almost always are forced to work as domestics for meager wages; Hope Lewis, *Universal Mother: Transnational Migration and the Human Rights of Black Women in the Americas*, 5. J. GENDER, RACE & JUST. 197, 197–206, 216–24, 227–29 (2001) (describing an in-depth analysis and a graphic account of the long tradition of migrancy among Jamaican women); both articles reprinted in JEANNE M. WOODS & HOPE LEWIS, *HUMAN RIGHTS AND THE GLOBAL MARKETPLACE: ECONOMIC, SOCIAL AND CULTURAL DIMENSIONS* 434–41 (2005).

7 Hope Lewis, *Lionheart Gals Facing the Dragon: The Human Rights of Inter/National Black Women in the United States*, 76 OR. L. REV. 567, 578 (1997). In this brilliant article, Lewis lifts the veil of invisibility from Jamaican women, who are forced to work in jobs that reinforce that reality that for Black women, born into poverty and denied social standing, there are few options. Working always to serve and care for the children and families of the rich and powerful. Who are these women? They are domestic workers and home health aids. They are assembly line workers, who stand on their feet all day for minimal wages. They endure all manner of indignities and often suffer in silence. Their lionhearted spirit comes from within and sustains them. See also Darlene Clark Hine, *Lifting the Veil, Shattering the Silence: Black Women’s History in Slavery and Freedom*, in *THE STATE OF AFRO-AMERICAN HISTORY: PAST, PRESENT, AND FUTURE* 223–49 (1986).

8 See BELL HOOKS, *SISTERS OF THE YAM: BLACK WOMEN AND SELF-RECOVERY* 29 (1993). In this important work about Black women and self-discovery, Hooks discusses the importance of Black women being able to tell their stories to heal the hurt. Like Lewis, the stories Hooks chooses to lift up are those of women who hurt without ever being regarded. Specifically, Hooks writes: “Many black women in the United States are broken-hearted. They walk around in daily life carrying so much hurt, feeling wasted, yet pretending in every area of their life that everything is under control. It hurts to pretend.

from the margins of exclusion into places where the privileged had long been sheltered from the harsh realities of black life.

During the Gordon Lecture, I was honored to meet members of Professor Gordon's family, including Sister Bernice Pulley, a native of Ruleville, Mississippi, who has lived in upstate New York for many years. Sister Pulley shared her amazing story with me. Her mother and Fannie Lou Hamer's mother both worked as domestics in the home of the infamous Senator James Eastland in Sunflower County, Mississippi. Pulley talked about how the two women saw so much evil and endured even more as Black low wage women workers who were economically exploited and socially disregarded. We talked often after we left Boston, and Ms. Pulley also contributed to a work in progress called: *Testimony—Stories of Black Women from the Mississippi Delta and other Parts of the State*.<sup>9</sup> This connection was made possible because of the bridge that was Hope Lewis.

Taking the easy way out is a privilege afforded to those who choose mediocrity as a way of life. Hard work and the truth do not sell and are often not profitable nor publishable. The real work comes from the underground—from a place where pages are drenched in blood—where people died to learn. It comes from the likes of Hope Lewis, a living treatise in the most eloquent sense, whose scholarship met the pavement. This scholarship that put a human face on suffering, was the lesson narrative of the Dred Scott<sup>10</sup> dilemma—a way for the excluded to understand their plight and have access to tools that connected them to others fighting against

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It hurts to live with lies. The time has come for black women to attend to that hurt." *Id.* at 29.

- 9 Jaribu Hill, *Testimony—Stories of Black Women from the Mississippi Delta and Other Parts of the State* (forthcoming 2019). This series features true stories of Black women who are movers and shakers. Beautifully photographed by Shiho Fukata, each woman's story is a celebration of courage and raw will.
- 10 *See* Dred Scott v. Sandford, 60 U.S. 393, 407 (1857). Here I metaphorically reference Dred Scott's dilemma, as a way of making the comparison between contemporary and historic forms of exclusion experienced by Black women, men and children and the denial of basic human rights to the legally binding exclusion experienced by Dred Scott where the U.S. Supreme Court delivered its pro-slavery decision. There the highest court in the land, held Scott was not a human being in the eyes of the law and thus he was not a citizen. Writing for the Court, Justice Roger Taney declared, "[A Black Man] had no rights which the white man was bound to respect." Many would argue and I am one to do so, that contemporary forms of institutional racism reinforce notions of inferiority, thereby justifying ongoing forms of racial exclusion and discrimination.



the same exclusion and denial of their right to live and breathe free. Merging theory with practice—with doing—helps explain the lockout and develops strategies for resistance and reframing the debate. Hope sought me out because she wanted to create a space for radical voices to share case studies and prototypes of contemporary field-work rooted in a living, breathing theory of change. Professor Lewis introduced risk-taking as a style of teaching worthy of attention. Her approach was more than cutting edge. It was before its time. Indeed, because there was and is a Hope Lewis, we are stepping into this necessary time zone—moving the needle—defying the mandates of our oppressors. This defiance is historic. Its reach stretches across generations.<sup>11</sup>

Hope's learning path was informed by real stories, testimonials of those living on the margins. Women trafficked to enter the industry of rape, captivity and death. African people languishing under systems of colonialism and neocolonialism. Children forced into slavery to weave carpets and sew trendy clothing for the rich and the rest of us. Black women workers toiling under Jim Crow working conditions.<sup>12</sup>

The Lewis model was informed by the global suffering of Black women. Through her teachings, we learned the universality of the plight of poor women of color. Understanding these connections is essential to obtaining an overall grasp of the full range of civil and human rights obstacles they face every day of their lives.<sup>13</sup> It is important to put a human face on the victims of capitalism

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11 Thavolia Glymph, *I'se Mrs. Tatum Now: Black and White Women and the Meaning of Freedom*, PHILLIS: J. FOR RESEARCH ON AFR. AM. WOMEN 1.1 (2010). Glymph traces the history of the status of Black women during slavery and their struggle to challenge systems of oppression (“The struggle of Black women to transform working conditions in domestic work during and after slavery took shape as a contest over small rights. . . They too challenged hierarchies of power”).

12 See generally MICHAEL KEITH HONEY, *BLACK WORKERS REMEMBER: AN ORAL HISTORY OF SEGREGATION, UNIONISM AND THE FREEDOM STRUGGLE* (1999). Honey shows extraordinary sensitivity and an uncommon understanding about the struggles of Black women factory workers who were leaders in the Memphis, Tennessee movement in the late 60's. They worked to organize unions in their workplaces and supported the “I am a Man” campaign led by Memphis sanitation workers in 1968. Alzada Clarke and Ida Leachman, union organizers, are among those featured in this riveting account.

13 See generally Deborah K. King, *Missing the Beat, Unraveling the Threads: Class and Gender in Afro-American Social Issues*, 22.3 THE BLACK SCHOLAR 36 (1992).

and imperialism. Their stories are the same.<sup>14</sup> Lewis' writings are measured, carefully crafted to not be mainstream or ordinary. She bypassed safe shallow waters to go straight to the deep end. Hers was a gift of bringing varied voices into a single room. Hope unselfishly provided opportunities for law colleagues, students, and members of the community to benefit from their collective visions, wisdom, and triumphs. She embodied the essence of living to learn. Just to run alongside her had to be enough; no one could ever catch up with her. Neither the nagging inconvenience of dialysis or failing vision kept Hope Lewis from carrying out her mission and breathing life into her legacy. She was prolific and approached each day of her life with a profound sense of urgency. It was this sense of urgency that compelled her to find new meaning in the law and all of its lofty principles. It was this sense of urgency that led her to produce legal writings that challenged the status quo and encouraged a body of reasoning that was not divorced from the injustices faced by the masses. Even the titles of Hope's articles suggested the writings would be beyond cutting edge. For example, Hope's article "Lionheart Gals Facing the Dragon: The Human Rights of Inter/National Black Women in the United States"<sup>15</sup> brings to life the reality of human suffering that is rooted in resistance and triumph, just as the great contemporary jazz singer Les McCann once sang about in his 1969 song "Compared to What."<sup>16</sup>

14 Jaribu Hill, *Threads of Common Suffering and A Victory We Must Claim*, 28 S.U. L. REV. 271, 272-73 (2001) ("The struggles of women of color for human dignity are the same all over the world. To unpack this sameness, contemporary forms of slavery, institutionalized racism and sexism, it is important that we leave no stone unturned. Race, class and gender oppression are brutal realities in the 21<sup>st</sup> century"). See also ANGELA Y. DAVIS, *WOMEN, RACE AND CLASS* (First Vintage Books 1983) (1981), for Davis's brilliant commentary on the ever-abiding legacy of slavery and its impact on the Black woman. She provides a framework for understanding the social standing and marginalization of Black working class women today.

15 See Lewis, *supra* note 7.

16 EUGENE MCDANIELS, "COMPARED TO WHAT" (Atl. Recording Corp. 1969). "Compared to What" is a social issue oriented jazz song, written by Eugene McDaniel and performed by acclaimed jazz pianist and vocalist Les McCann and blues/jazz legend Eddie Harris. One of the most celebrated recordings of this insightful musical piece is featured on *SWISS MOVEMENT: MONTREUX 30TH ANNIVERSARY EDITION* (Atl. Recording Corp. 1996). I reference it here because the song's message is analogous to Hope Lewis' brand of scholarship which brings to life the reality of human suffering. Like many songs written during the tumultuous Sixties, "Compared to What" expresses the sign of the times. So too does Lewis's legacy of a learning style deeply rooted in resistance

Professor Hope Lewis was a leader in the field, who understood the importance of discourse and teaching grounded in human rights themes. It is no wonder she was internationally recognized as a legal scholar and commentator on human rights. Imagine my overwhelming joy when I learned in 2001, she was awarded the Haywood Burns/Shanara Gilbert Award. As a CUNY School of Law alum, close friend, and student/mentee of Haywood Burns,<sup>17</sup> I can think of no one else who embodied Haywood's passion, intellect, and commitment to law as a means of seeking truth and justice and human rights for all.

In June 2005, I received my copy of *Human Rights and the Global Marketplace—Economic, Social and Cultural Dimensions*. It was a gift from Hope. Inside she wrote:

To Jaribu—The struggle continues. . . Thank you for taking the time to contribute to Northeastern's first consultation on ESC. As the 2005 Valerie Gordon Human Rights Lecturer, you have helped the Program on Human Rights and the Global Economy to get off to a great start! I hope this work will contribute in some way to the wonderful work of the Mississippi Workers' Center for Human Rights. Respect and Peace, Hope, 6-20-05.

In *Human Rights and the Global Marketplace—Economic, Social and Cultural Dimensions*, Lewis and Woods prove once again, that it takes a woman to put a human face on worldwide suffering. Their work is extremely powerful and is filled with narratives, articles and a rich array of notes and questions, answers, and premises. Indeed, the *Global Narratives/Global Realities* section of the book covers some of the most critical examples of human

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and triumph.

17 Haywood Burns was the first Dean of the City University of New York School of Law (CUNY). While attending the International Jurist Conference in South Africa, he and Professor Shanara Gilbert were tragically killed in a car accident. In one day, CUNY lost its first Black tenured Professors and the world lost a giant in law and in the fight for human rights and freedom. See Karen W. Arenson, *W. Haywood Burns, 55, Dies; Law Dean and Rights Worker*, N.Y. TIMES (Apr. 4, 1996), <http://www.nytimes.com/1996/04/04/nyregion/w-haywood-burns-55-dies-law-dean-and-rights-worker.html>. M. Shanara Gilbert, *45, a Law Professor*, N.Y. TIMES (Apr. 4, 1996), <http://www.nytimes.com/1996/04/04/nyregion/m-shanara-gilbert-45-a-law-professor.html>.

suffering and global exploitation.<sup>18</sup> Examples of issues discussed in the book include; modern-day slavery, human trafficking, trade for the rich and poverty for the poor, NAFTA's failure to improve the lives of the impoverished, the fight for dignity and humane working conditions waged by domestic workers in the U.S. and the plight of the Palestinian people, seen through the lens of human rights.<sup>19</sup> So much is contained in this brilliant text, that it is truly a powerful learning tool!

Publishing dangerous material in a society that encourages avoidance of such truths is a revolutionary act. It is this merger between biting commentary, journalism, and legal reasoning that provides the best example of how law can mirror life and provide a roadmap for dismantling repressive schemes and structures that hold their victims hostage and shore up a relentlessly anti-people status quo. This work must be shared and integrated in law, social science, and human rights curricula across the US and abroad. I am sure this is being done; however, its circulation numbers must swell.

## II. The Legacy

What is the Hope legacy? It is one that gives us new frames, engaging analyses, and a chance to swim in the deep end—to rattle and shake the walls of the tower for greater access and a wider stream of brave voices in academia. It is one that defies class strata and forces inclusion of those demanding to be seen and heard. This work is exactly what the human rights movement of educators, students, and advocates needs to explain the misery and make human rights for all a reality.

Lewis' work is part of a body of work that amplifies women's voices and celebrates their scholarly and visionary contributions to revolutionary feminist theory and practice. Professor Lewis and other leading Black feminist writers, provide vivid examples of repression and resistance captured in actual stories of Black women fighting against the harsh realities of race, class, and gender oppression. Among these strong voices is Beverly Bell, whose stories of the survival and resistance of Haitian women, like Lewis' stories about the similar stories of Jamaican women, invite teachers and students to learn from these courageous women, who overcame insurmountable

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18 See *Chapter 1: Global Narratives/Global Realities*, in Woods & Lewis, *supra* note 6, at 3-40.

19 *Id.*

odds to demand freedom and human rights.<sup>20</sup> Black women who write about the dispossessed, the murdered in the dark—behind closed doors, tell stories of love-beatings, rapes, trauma, and death. This is the work Hope Lewis dared to do: bringing these women into the ivory tower; using their stories of triumph and resolve and sharing accounts of how they broke the chains of victimhood to stand in their own skin and claim their rightful place in society and community. These stories are shared across many waters from the Mississippi Delta to Southern Africa. The plight of Zimbabwean farm women, who are the constant victims of sexual and economic oppression, is yet another example of the “sameness” experienced by Black women across the globe.<sup>21</sup> Reminiscent of slavery, these young Black women were victims of rape and often forced to bear the children of their rapists. These unsettling accounts describe how they learn early on the sting of abandonment and desperation. Here, I share my reaction to their stories told during our Black Women’s International Roundtable:

*No use waitin’ for girlhood to return  
it left in the chilly winds of winter—sold in a box-cart—  
in a field of stolen heritage  
a high-jacked birth-rite  
The innocence gone from her eyes  
No dolly can bring it back  
No fairy tale slumber  
A lullaby snatched from a mother’s throat<sup>22</sup>*

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20 BEVERLY BELL, WALKING ON FIRE: HAITIAN WOMEN'S STORIES OF SURVIVAL AND RESISTANCE 131–33 (2001). When speaking of resistance, Vita Telcy, one of the Haitian women featured in Bell’s powerful work, wrote, “Still, we as women resisted and forced the situation to change. Not in an isolated fashion, no way—this was done in an organized way. And each victory reinforced our courage because that are were doing good work.” *Id.* at 131.

21 See DEDE ESI AMANOR-WILKS, IN SEARCH OF HOPE FOR ZIMBABWE’S FARM WORKERS 19 (1995). Amanor-Wilks gives us a riveting account of the tragic and dehumanizing lives of young Black women farmworkers in Zimbabwe. *Id.* at 19. As one Zimbabwean farm worker noted: “They want us to be down, down, down until we die.” *Id.* Amanor-Wilks carefully weaves together facts and figures with stories of sexual abuse and rape. *Id.* at 31–38. Black farm worker women in this important work are forced into sexual arrangements with their bosses despite their husbands’ and fathers’ objections. *Id.* at 35–27. Many suffer beatings and terminations if they refuse. *Id.*

22 Jaribu Hill, original work written on the occasion of the Black Women’s

It is also important to note Black women in food processing industries in the Mississippi Delta are also subjected to sexual abuse, assaults, and rapes.<sup>23</sup> Indeed, they too must often accept unwanted advances or risk termination.<sup>24</sup> Despite many changes taking place in the industry, bathroom rights are still denied in poultry and fish plants across the Deep South and other parts of the U.S.<sup>25</sup> These are the connections Lewis and her contemporaries found as they ventured beyond the walls of higher learning. Professor Lewis concerned herself with the sufferers—the working class—those languishing in the underclass. She archived their suffering in academic journals that often failed to include realities of legally sanctioned exploitation. Lewis intentionally linked these realities with her quest to breathe life into case studies and late breaking news stories about those who were most vulnerable, who had no expectations of privacy, protection, or relief. Hope understood the interrelatedness of their stories with those about the Jamaican women, whose lives she chronicled in her important work.<sup>26</sup> She carefully marshaled through mounds of abstractions and dense assertions and crafted substantive accounts of failed systems and dismantled safety nets. Lewis' understanding of the relationship between the global economy and human needs allowed her to offer alternatives to the status quo. Her work shined a light on the lack of accountability and successfully made the case for the need to examine systems and structures that negatively impact the lives of Black women at home and abroad. These are the connections that must be at the very center of the theory and practice going forward. Many have attempted to develop scholarly Black feminist theory in a vacuum. Their writings often are void of

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International Roundtable at Harare, Zimbabwe (Aug. 2001) (unpublished work on file with the author). The Roundtable brought together 30 human rights defenders from Zimbabwe, Johannesburg, Egypt, Ethiopia, Canada and the U.S. to celebrate human rights efforts struggles led by women in the Africa Diaspora.

23 See generally THE FOOD CHAIN WORKERS ALL. & THE SOLIDARITY RESEARCH COOP., *No Piece of the Pie: U.S. Food Workers in 2016*, November 2016, available at [http://foodchainworkers.org/wp-content/uploads/2011/05/FCWA\\_NoPieceOfThePie\\_P.pdf](http://foodchainworkers.org/wp-content/uploads/2011/05/FCWA_NoPieceOfThePie_P.pdf).

24 See generally Id.

25 See Katie Gibson, *Denied Bathroom Breaks, These Workers Must Resort to Diapers*, CBS MONEYWATCH, May 12, 2016, <https://www.cbsnews.com/news/denied-bathroom-breaks-these-workers-must-resort-to-diapers/>.

26 See Lewis, *supra* note 6.



human experiences. While some profess to address the intersection between race, class, and gender, they lean heavily on race and gender frames and fail to address class oppression. It is also true that the U.S. government sees this necessary work as dangerous. The idea that masses of Black people, living in poverty would join with other poor people and launch campaigns to demand that the U.S. ratify the Convention on Economic, Social and Cultural Rights, is its worst nightmare.

Lewis' scholarly works brought to light the race, class and gender oppression suffered by Black transnational women and did much to create space for expanded notions of intersectionality.<sup>27</sup> This attention to the full range of injustices experienced by Black women is what sets Hope Lewis apart from many Black feminist writers. She and other brave voices rejected the repressive and ever conforming writing trends and helped to bring to the fore an important theoretical framework to challenge learning models that stifle efforts to shift the paradigm. They offer a body of learning that provides a roadmap to dismantling structural racism and patriarchy.

Now Hope joins other Warrior Women Ancestors—Ida B. Wells, Audre Lourde, Constance Baker Motley, Nina Simone, Novella Nelson, Abbey Lincoln, Sheila Abdus Salaam, and countless others. I imagine she was welcomed into the next lifetime by another great Black Woman Warrior Scholar, Margaret Walker Alexander. Her struggle to remain relevant and true is one that reminds us of Hope's personal and political struggles. In *On Being Female, Black and Free*, Walker Alexander wrote, "Every day I have lived, however, I have discovered that the value system with which I was raised is of no value in the society in which I must live. This clash of my ideal with the real, of my dream world with the practical, and the mystical inner life with the sordid and ugly world outside—this clash keeps me on a battlefield, at war, and struggling, even tilting at windmills. Always I am determined to overcome adversity, determined to win, determined to be me, myself at my best, always female, always black and everlastingly free."<sup>28</sup> DREAM OUTSIDE YOUR COMFORT

27 Lewis, *supra* note 6, at 576-77.

28 *On Being Female, Black, and Free*, in *ON BEING FEMALE, BLACK, AND FREE: ESSAYS BY MARGARET WALKER, 1932-1992*, at 3, 8 (Maryemma Graham ed. 1997). Walker Alexander's compilation of essays provide, like the writings of Hope Lewis, a glimpse into the complexities of being Black and Woman, as well as a deep dive into complex issues we confront today. Personalizing and Humanizing Black women, who continue to be socially and economically excluded from the structures, policies and institutions that control their lives.

ZONE—THAT IS WHAT HOPE LEWIS DID EVERYDAY OF HER LIFE AND IT WAS A LIFE WELL-LIVED.

### III. Going Forward—Honoring Hope with our Work!

When I think about the legacy and the gift of Hope Lewis, I think about the marching orders that should be embraced by those of us who use our bar cards to challenge unjust laws and fight for remedies where rights are denied. In January 2016, I gave them to Yale Law Students at the Rebellious Lawyering Conference:

1. We must work until all vestiges, all badges and incidents of slavery are stripped away.
2. We must work until no one is hungry, homeless, illiterate, wrongfully incarcerated, denied reentry when released, murdered in custody, denied a living-wage, denied a promotion on the basis of race or gender.
3. We must work until no more Black Trans women are murdered.
4. We must work until no more Black bodies lie in pools of blood under the color of law.

And the list goes on and on.<sup>29</sup>

We must be fearless and overly prepared to stand with those who literally have no one else! That is what I take away from the extraordinary legacy of Hope Lewis!

Hope joins a long line of truth telling freedom fighters, who didn't give an inch but walked mile after mile to bend and break the rules, to breathe new life into words and deeds. Rest on Lionheart Gal; you faced the Dragon for all of us!!! Hope Lewis, Presente!!!

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The crippling effects of triple oppression (race, class and gender) experienced by Black women in Walker Alexander's time are once again brought to light in the works of Hope Lewis.

29 Jaribu Hill, Excerpts from Keynote Address at the 2016 Rebellious Lawyering Conference at Yale University School of Law (Feb. 17, 2016).



## Imagining Hope Happy

*Ibrahim J. Gassama\**

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\* Frank Nash Professor of Law. Dedicated to Edith Louise Stephenson and Blossom Stephenson who raised a “lionheart gal,” to help us remember that you can have joy and hope even as you confront the dragons of our world. A “lionheart gal” is a courageous woman in Jamaican dialect. See Hope Lewis, *Lionheart Gals Facing the Dragon: The Human rights of Inter/national Black Women in the United States*, 76 OR. L. REV. 567 (1997). See also HONOR FORD-SMITH & SISTREN, *LIONHEART GAL: LIFE STORIES OF JAMAICAN WOMEN* (1986).

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The human heart has a tiresome tendency to label as fate only what crushes it. But happiness likewise, in its way, is without reason, since it is inevitable.

Albert Camus, *The Myth of Sisyphus*

## I. INTRODUCTION: FLOATING BODIES

A recent headline says: “Bodies of 26 African Girls Found floating in Mediterranean Sea.”<sup>1</sup> The girls, teenagers, are believed to be migrants from West Africa.<sup>2</sup> Other girls were found clinging to a partially sunken rubber boat.<sup>3</sup> An investigation would take place, they promised.<sup>4</sup>

I paused to think about those girls at the moments of their births and the joy those occasions brought to someone, and I reflected on the arcs of their hopes. I saw them as children, perhaps shielded from the brutal logic of existence. I cautiously approached the moment when they were impelled to embark on their final journey, like so many others before and after, through deserts and oceans of indifference, propelled by hope, in search of joy. When was it that pushing their rock proved too big a burden? When did the utter indifference of their God or the great immensity become apparent and irrefutable? When did the horror finally take hold? Did they, like Josef K, perceive a glimmer of light in the far distance and hope for one last time for someone to help them?<sup>5</sup> For a way to survive the enveloping darkness one more time? Conrad said that, “we live in the flicker—may it last as long as the old earth keeps rolling!”<sup>6</sup> Yes, but for too many still, the flicker is an eternity of horrors.

My intellectual relationship with Hope spanned the decades of our lives as activists and academics, trying to translate our hard-won experiences, our thoughts, and our faiths into life lessons for ourselves and those we have been privileged to encounter. Reflecting upon this relationship, I am struck now by how closely we followed a fixed, almost scripted, pattern of dialogue. Neither one of us could be described as idealistic. But while my version of realism took me inevitably in the direction of despair, unable to rationalize the horrors that inhabit all the “dark places of the earth,” Hope demonstrated

1 See Yaron Steinbuch, *Bodies of 26 African Girls Found Floating in the Mediterranean Sea*, N.Y. POST (Nov. 7, 2017, 8:52 AM), <https://nypost.com/2017/11/07/bodies-of-26-teenage-african-girls-found-floating-in-mediterranean-sea/>.

2 *Id.*

3 *Id.*

4 *See id.*

5 As Josef K faced death, his resignation to his fate was punctuated by a brief moment of hope as he saw, “Like a flash of light, the two casement windows” parting to reveal a human figure. He wondered briefly whether the figure was someone who cared and whether help was still possible just before he was stabbed. *See FRANZ KAFKA, THE TRIAL* (Alfred A. Knopf ed., 1956), 164-65.

6 *See JOSEPH CONRAD, HEART OF DARKNESS* 5 (Simon & Schuster 1972).

an unyielding commitment to, well, hope. We both read Conrad, Camus, De Beauvoir, Kafka, and Bell, and watched and dissected Coen Brothers' movies, but while I was left with a bitter after taste and a persistent cynicism about even basic concepts like humanity or human progress, Hope found a joy in life that was best captured in Camus' affecting essay, *The Myth of Sisyphus*:

I leave Sisyphus at the foot of the mountain! One always finds one's burden again . . . . The struggle itself toward the heights is enough to fill a man's heart. One must imagine Sisyphus happy.<sup>7</sup>

If Camus could call on us to imagine Sisyphus happy, I would like to reflect briefly on Hope's happiness. Fortunately, mine is a much easier task compared to Camus'. Hope's happiness was not hard to imagine. Indeed, if you knew her at all as a friend, colleague, professor, or mentor, you have no need to imagine her happy. All you need are your memories.

Hope was my friend. Speaking of friendship, Emerson said:

My friends have come to me unsought. The great God gave them to me. By oldest right, by the divine affinity of virtue with itself, I find them, or rather not I, but the Deity in me and in them derides and cancels the thick walls of individual character, relation, age, sex, circumstance, at which he usually connives, and now makes many one.<sup>8</sup>

All the walls came down and we found it in each other. There is a freedom that comes with deep friendship, a freedom that allows one to push the outer edges of thought protected by the knowledge that your friend will not let you disappear into hopelessness or incoherence, no matter how hard you may try. Friendship provides rescue; it is a home you can always go back to without the disempowering prospect of judgment. Except of course in Hope's case, with her inevitable "I told you so Ibrahim. You just won't do what I tell you." But that was just punishment for not following her

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7 ALBERT CAMUS, *THE MYTH OF SISYPHUS AND OTHER ESSAYS* 123 (Alfred A. Knopf ed., Justin O'Brien trans., 1967).

8 *THE SELECTED WORKS OF RALPH WALDO EMERSON* 203 (Brooks Atkinson ed., Modern Library 1968).

plans that were “for my own good.” Truth be told, I would trade for such punishment any day when the alternative is judgment by strangers. Hope’s friendship was always a secure and welcoming home for me. But that was merely her trademark, a vital part of her *joie de vivre*. It was extended to so many others.

I marveled at Hope’s relentless pursuit of meaning and her enduring commitment to lighting paths forward through the darkness that I was resigned to embrace. I tested her whenever I could. I complained, for example, that the only problem I had with Existentialism was that it retained a glimmer of hopefulness that humans could transcend the burden of existence. In their dreams, it turns out, even Existentialists don’t die. Their hope persists. So did she.

Sometimes to provoke Hope, I would argue that no set of ideas comes close to matching the jejune hopefulness, dangerous naivete, and insufferable narcissism of her discipline, the modern human rights movement—with all its happy talk about the inherent dignity and equality of mankind and its vainglorious obsession with standard setting. “Hope,” I would say, “don’t you see, you lost the fight the moment you had to remind humans that genocide was a crime!”

Hope met the challenge, not just as a generous and patient friend but also as a measured scholar. She would draw me into her work, brushing aside my rather gleeful fascination with the absurd. She demanded that I give an evaluation of her work, within its own terms. Her examination of intractable problems like gender violence, FGM, racism, discrimination against people with disability, and socio-economic inequality are familiar to many in the legal academy and elsewhere. What may not be so readily apparent in her work is the deliberate consciousness with which she pursued such work without regard to the likelihood of resolution in the time she knew she had left or indeed in the time we humans have left. Hope protected and defended her right, and the right of the people she was part of and wrote about, to imagine a better world even under the most trying and absurd circumstances.

Kafka argued that logic “cannot withstand a [human being] who wants to go on living.”<sup>9</sup> I believe him because I see such evidence everyday and because I knew Hope Lewis. My dark logic inevitably conceded under assault from her relentless humanism. Hope

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9 KAFKA, *supra* note 5, at 286.

embodied the human spirit that would rather confront obstacles known and unknown than accept the fate of a quiet death. I was not privileged to know any of the courageous young women whose journey took them to the Mediterranean, nor millions of our fellow beings from the Yazidis of Iraq to the Rohingyas of Myanmar, but I knew Hope. She was of them and by them and for them. For those whose lives she touched, the flicker always held out the possibilities of survival, hope and happiness.

## II. A FOUNDATION OF RESILIENCE AND RESISTANCE

*I leave Sisyphus at the foot of the mountain! One always finds one's burden again . . . The struggle itself toward the heights is enough to fill a man's heart. One must imagine Sisyphus happy.*

Albert Camus, *The Myth of Sisyphus*

Hope's imagination and the joy that came with it were built on a foundation of resilience and resistance immediately traceable to her mother and grandmother, but in truth, its origins are in the irrepressible human desire to transcend physical and spiritual boundaries that are constructed and continually reinforced to separate us from our humanity. Hers was a tough life, filled with innumerable challenges, but no one who encountered Hope Lewis found in her demeanor, ideas, or publications any evidence of even a shadow of resignation or defeat. Instead, they would testify to resilience and resistance that fed a boundless imagination wrapped up in a purposeful embrace of optimism. Anger and hate found no refuge within her soul. (Well, I exaggerate! There were occasions when she assured me she would murder "those people" if they messed with her grandmother! As for what she said about various deans, well that was just Hope being a law professor!).

Yes, it has been stated that "existence precedes essence" but we can't ignore, as De Beauvoir insisted, that not all existence derives from equal origins. Furthermore, long before one is in a position to develop one's essence, to be the agent of one's own change, so to speak, you do exist at the mercy of circumstances, particular to you and capable of limiting or expanding the scope of your life. I wish all of humanity could have had Hope's circumstances, because the love, inspiration, and material investment of her family, especially two remarkable women, her mother, Blossom Stephenson, and her grandmother, Edith Louise Stephenson, endowed Hope with a

character that was more than capable of approaching the tribulations of everyday life with rock solid resilience and self-assurance.

Hope was also fortunate to grow up in the vibrant world of the Caribbean immigrant community of Brooklyn, N.Y. As a result, Hope made a conscious commitment to a life that did not shy away from the challenges she and others like her faced, and she chose to do so with grace and a *joie de vivre* that would amaze even a dyspeptic soul. I confess to the most painful thing my friend said to me just over a year ago. She said, “Don’t give up on me Ibrahim.” She caught me! And not for the first time; my only honest response was silence. I am at peace knowing that Hope understood that not all of us are gifted with her unique capacity to face the absurd with imagination, and to resist without losing our joy, faith and hope. I channeled Fanon; she, Walcott.<sup>10</sup>

Two aspects of Hope’s foundation need further elaboration: the first is that Hope benefitted from a tradition of self-directed women who made no apologies and demanded no sympathies as they transgressed the limits that time, identity, and circumstances sought to impose upon them. Hope’s grandmother, for example, did not seek her husband’s permission to leave Jamaica to come to the United States. The second aspect is that Hope was the product of a particular immigrant experience at a critical point in modern globalization. This experience began with the first ships that left the African coast five hundred years ago with their ignoble cargoes of humanity consigned as chattel. For these people of the diaspora, resilience, imagination, and joy were essential aspects of their strategies of survival and resistance. Pause for a minute to reflect on what it took for the victims of this African genocide to hold on to their humanity; to retain, sustain, and propagate their character and

10 Frantz Fanon, West Indian psychiatrist, philosopher, and Pan-Africanist revolutionary who participated in the Algerian struggle for independence from France and authored several works, including *The Wretched of the Earth*, that have influenced anticolonial movements and students of critical and post-colonial studies. Sir Derek Walcott was a renowned West Indian poet who received many honors for his works including the Nobel Prize for literature in 1992. See generally FRANTZ FANON, *WRETCHED OF THE EARTH* (Richard Philcox trans., Grove Press 2004) (1961); see also Samuel Singler, *Examining the Dynamics of Decolonisation in Fanon’s The Wretched of the Earth* (May 3, 2016), <http://www.e-ir.info/2016/05/03/examining-the-dynamics-of-decolonisation-in-fanons-the-wretched-of-the-earth/>; William Grimes, Derek Walcott, Poet and Nobel Laureate of the Caribbean, Dies at 87, N.Y. Times, March 17, 2017. <https://www.nytimes.com/2017/03/17/books/derek-walcott-dead-nobel-prize-literature.html?mtrref=www.google.com>



their joy, over centuries of unstinting bondage, abuse, humiliation, and perversities? Wasn't every moment itself a burden of Sisyphean magnitude? Like the prophet Jeremiah, would these people not have been justified in lamenting to their gods:

“Why did I come forth from the womb  
to see toil and sorrow,  
and spend my days in shame?”<sup>11</sup>

But they persisted, these people, these “Wretched of the Earth.”<sup>12</sup> They survived, and they gifted to the world another wondrous example of unbreakable human commitment to move forward in the face of adversities and calamities. Recall that in her beautiful and subversive piece, *Lionheart Gals*, Hope quoted Audre Lorde, reminding us that “[t]o survive in the mouth of this dragon we call America, we have had to learn this first and most vital lesson—that we were never meant to survive.”<sup>13</sup> Yes, when the plan is genocide, existence is victory. Note further that Hope followed that with a quote from a version of Psalm 137, embraced by Rastafarians and popularized by the reggae group, the Melodians:

“By the rivers of Babylon, there we sat down, yea, we wept, when we remembered Zion . . . . For there they that carried us away captive required of us a song . . . . How shall we sing the Lord’s song in a strange land?”<sup>14</sup>

Still they sang, not for their tormentors, but for themselves, songs of freedom and redemption in a strange land, and they prospered and they gave us Hope. We would be remiss not to note that theirs were borrowed words that they then employed not only in service of their struggles for self determination, but also to ratify and extend chains of human solidarity across space and time. All that separated the Babylonian Captivity from the Middle Passage was a flicker.

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11 *Jeremiah* 20:18 (New Revised Standard Version).

12 See Fanon, *supra* note 10.

13 See Hope Lewis, *Lionheart Gals Facing the Dragon: The Human Rights of Inter/National Black Women in the United States*, 76 OR. L. REV. 567, 567 (1997).

14 *Id.* at 568 (quoting *Psalm* 137 (King James Version) accord THE MELODIANS, RIVERS OF BABYLON (Beverly’s Records 1970)).

Hope understood that her people, these children of the diaspora, the survivors, as well as those who fell along the way like the 26 girls in the Mediterranean, were not the only examples of human desire and capacity to build the lives they were capable of imagining under the most trying of circumstances. It is therefore completely unsurprising that in her considerable body of work, she took up diverse hopes and dreams. With resolute discipline, Hope made vital connections in scholarship and advocacy between seemingly discrete struggles separated by geography, time, and ignorance. She forged from the chains of genocide and a host of other crimes against humanity, sterling bonds of friendships and solidarity, of understanding and empathy that reached across the boundaries of identity, time, and space.

### **III. SCHOLARSHIP AND SERVICE IN PURSUIT OF GLOBAL INTERSECTIONS: FROM TRANSAFRICA TO NORTHEASTERN UNIVERSITY**

Shortly after graduating from law school, Hope worked as a research fellow at TransAfrica. This was during the height of the Free South Africa Movement that TransAfrica and its founder, Randall Robinson, were leading. Though her time at TransAfrica was brief, Hope came to embody the values, goals, and spirit of the insurgent organization and movement. She had a positive disposition, irrepressible imagination, and palpable energy that helped to moderate her loud voice and uncompromising approach to fighting injustice. Few of her colleagues then had any true sense of the extraordinary medical challenges that she was already a veteran at managing. She kept her personal challenges private even as she embraced and championed the causes of others.

Hope made at least two important contributions that suggested the direction that her later academic work would take. In the midst of the anti-apartheid struggle when efforts were primarily focused on ending the racist apartheid regime, Hope was among voices calling for a contemporaneous focus on gender discrimination and violence against women. These ills were unhappily represented not only within the apartheid system but, within the ranks of the anti-apartheid revolutionary movement, as well as in the broader struggle for justice in the Third World. It is difficult now to appreciate how few of us then were willing to expand beyond a singular, race-focused struggle against apartheid, neo-colonialism, and imperialism. Of course, Hope was also a romantic, but she was not

willing to suppress the contradictions within the anti-apartheid or anti-colonialism struggles until some point in the future, especially as they related to gender violence and discrimination.

Another of Hope's important contributions was in developing a historical record to help TransAfrica frame its outsider activism within the larger context of African-American contributions to the making and implementation of US foreign policy.<sup>15</sup> As a researcher, she helped highlight the impactful roles of African-Americans in the US Foreign Service to ensure that the historical record would see TransAfrica as not just a crucible or agitator of a mass political movement, but also transformational in scope and impact. She wanted TransAfrica to be understood properly as a curator of the historical memory of African people, a producer of knowledge and part of a continuum of visionary leadership in centuries-long resistance to an anti-human global order.

As an academic, Hope embraced an approach that was analytically rigorous, transparent, imaginative, courageous, and empathetic. Her frequent dedications in her publications to her mother and grandmother seem to me many things: an expression of gratitude to those who nurtured her intellectual curiosity, an affirmation that for her, scholarship was not impersonal, and a statement of resistance against the broader war on memory, perhaps the most insidious of all the challenges plaguing subordinated communities everywhere. The willingness to forgive is virtuous, but ignorance of the past is suicidal. Hope's scholarship marked our existence and testified to a culture of resistance as much as it mapped out strategies to survive, if not win, the future.

There is a statement in one of Hope's early publications that I consider her "Apologia Pro Vita Sua."<sup>16</sup> She wrote:

As an African American feminist law professor who is visually impaired and the daughter of immigrants,

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15 See Hope Lewis, *A Retrospective: Blacks In U.S. Foreign Policy*, Introduction to TRANSAFRICA FORUM (1987). See also Hope Lewis, "New" Human Rights? U.S. Ambivalence Toward the International Economic and Social Rights Framework, in BRINGING HUMAN RIGHTS HOME: A HISTORY OF HUMAN RIGHTS IN THE UNITED STATES 100-01 (Cynthia Soohoo et al. eds., abr. ed. 2007).

16 Translated as "A Defense of One's Life." This is a reference to the classic work of John Henry Cardinal Newman defending his faith after he came under attack because he had left an influential position in the Church of England to join the Catholic Church. See JOHN HENRY NEWMAN, *Apologia pro Vita Sua* (Ian Ker ed. 1994).

I am often torn as to which social justice organizing conference to attend first on any given day . . . Despite its limitations, [*the international human rights*] movement is at its best when it undermines the isolation that oppressed peoples and individuals can experience. Human rights can serve as a basis of coalition across geographic, political, gender, race, and physical boundaries.<sup>17</sup>

The language is classically Hope's, but you can hear heavy traces of generations of women that came before her testifying defiantly to the everyday reality of their lives. Hope was unapologetic yet nuanced about her conscious choice to engage a discipline and a movement that had come under incisive and sustained attack from many close colleagues. Hope stood her ground and made critical contributions to the field. Hope did not stretch to seek complexity. But complexity was her provenance and intersectionalities were the natural exposition of her existence at the heart of the empire. These became the method through which she captured the essence of her academic life.

In *Lionheart Gals*, Hope elaborated further on her academic mission when she tackled the oppressive transnational circumstances that brought women just like her mother and grandmother to the United States:

How do these Black women escape or resist the centers of power they encounter in their inter/national struggle to survive? Indeed, can legal scholarship contribute to a deeper understanding of the conditions under which they live? Without such an understanding, it will be impossible to develop policies that would help to alleviate those abusive conditions.<sup>18</sup>

Hope brought human rights home. She made the international local and vice versa. She dismissed the artificial and mendacious divide between domestic civil rights and international human rights that existed in the West, as well as other equally pernicious divides

17 Hope Lewis, *Global Intersections: Critical Race Feminist Human Rights and Inter/National Black Women*, 50 ME. L. REV. 309, 309–10 (1998) (footnote omitted).

18 Lewis, *supra* note 13, at 573.

that were maintained elsewhere.<sup>19</sup> She rejected false dichotomies like law and politics, and reactionary hierarchies that long obfuscated the enormity of the global human rights deficit. The casebook she co-authored with Professor Woods was anchored by these principles and it has helped enormously to bring so-called economic and social rights front and center even as it deepened our appreciation of the inextricable links among all the human values we refer to as rights.

One other aspect of Hope's academic contributions is worth emphasizing. Hope is what my late friend, Professor Keith Aoki, would call an "Institutionalista." It is a term Keith and I embraced and attached to colleagues who work relentlessly not just to develop and propagate their ideas but also to bring other people and ideas together. We believed that Institutionalistas do essential work, in the trenches of academia, so to speak, to further the development of knowledge. Read her submission on female genital cutting, in the Oxford Encyclopedia of Human Rights, for example, to appreciate her skill in this regard.<sup>20</sup> Appreciate how she managed diverse transnational perspectives in order to synthesize a progressive path. You also see evidence of this quality in her work on violence against women with disabilities.

It is said that Existentialists embrace the God that consumes them and that it is through humility that hope enters in. Hope, would of course object strenuously at any intimations of her being an Existentialist. But of course her objections have never stopped me before and they won't now. So I conclude that were she to object, it would merely reflect the humility with which she approached her purpose on this earth. Regardless, Hope embraced her existence and her cause. She lived the life she was bequeathed. She did something! Her numerous and diverse contributions reflect all she ever aspired to be, which was to be human in the sense that is still to be discovered by so many.

#### IV. CONCLUSION

In this game that we are playing, we can't win. Some kinds of failure are better than other kinds. That's all.

(Winston Smith) George Orwell, 1984

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19 See, e.g., Lewis, "New" Human Rights? U.S. Ambivalence Toward the International Economic and Social Rights Framework, *supra* note 15, at 106–07, 111–12.

20 Hope Lewis, Female Genital Mutilation and Female Genital Cutting, in 2 Encyclopedia of Human Rights, 200 - 13 (2009).

Just as in her own life where she refused to surrender to extraordinary medical challenges that many of us would have yielded to much sooner, Hope refused to concede to hopelessness in the face of the enormous obstacles facing the modern human rights movement. Unlike Orwell's Winston Smith, Hope made no concessions to despair. She was realistic about the odds, always, for herself, and for humanity. Yet Hope preferred her courage and her reasoning without apology and chose to live her life without appeal. Needless to say, were you to picture Hope in Orwell's dystopian world of *1984*, she would of course be Julia who could not accept that "there was no such thing as happiness" or "that the individual is always defeated."<sup>21</sup>

Looking now at her time on this earth, we will of course regret that circumstances did not permit her to do more. However, we know in our hearts that there is never enough time for anyone. There comes a point for all of us when no further objections can be made, no more appeals are left. It may seem in the moment to us that the verdict came in long before, perhaps even at the moment of birth. The whole process then would appear to have been no more than the removing of obstacles in order to reveal even more obstacles. Still, in Hope's time with us we have seen the choice to rejoice reaffirmed. Hope, like Derrick Bell's Geneva Crenshaw, would, I am sure, insist that we "rejoice in the memory of 'the many thousands gone,'"<sup>22</sup> the men and women who pushed rocks all these years past. She would insist that we "be worthy of their courage and endurance, as of our own hopes, our own efforts" and that we "take up their legacy of faith and carry it forward into the future for the sake not alone of ourselves and our children, but of all human beings. . . ."<sup>23</sup>

I close with a poem, a prayer if you will, in support of our eternal yearnings represented in our hopes and our imagination. It came from the imagination of another child of the diaspora, Derek Walcott:

### The Season of Phantasmal Peace<sup>24</sup>

21 GEORGE ORWELL, *NINETEEN EIGHTY-FOUR* 138 (1949).

22 DERRICK BELL, *AND WE ARE NOT SAVED: THE ELUSIVE QUEST FOR RACIAL JUSTICE* 257 (1987).

23 *Id.*

24 DEREK WALCOTT, *The Season of Phantasmal Peace*, in *COLLECTED POEMS 1948-1984*, at 464 (1986).

Then all the nations of birds lifted together  
the huge net of the shadows of this earth  
in multitudinous dialects, twittering tongues,  
stitching and crossing it. They lifted up  
the shadows of long pines down trackless slopes,  
the shadows of glass-faced towers down evening streets,  
the shadow of a frail plant on a city sill—  
the net rising soundless as night, the birds' cries soundless,  
until  
there was no longer dusk, or season, decline, or weather,  
only this passage of phantasmal light  
that not the narrowest shadow dared to sever.

I say Amen to that.

\* \* \*

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## The American Declaration of the Rights and Duties of Man: Using a Human Rights Framework to Deconstruct Systemic Police Misconduct Against Low-Income Women of Color

Neda Saghafi\*

### Abstract

*The history of hierarchical identities has become enmeshed in U.S. policing. Given the multiple forms of discrimination that arise from intersecting identities, low-income women of color are at high risk of police misconduct.*

*The existence of violent, hegemonic masculinity in police culture, in conjunction with problematic policing policies, such as discriminatory Terry stops, increased militarization in policing, and inequitable incarceration rates, have disproportionately impacted low-income women of color. Such disparate effects work to maintain societal hierarchies that perpetuate the marginalization of low-income women of color. U.S. response to police misconduct has proven insufficient. Adopting a human rights framework into domestic law can begin the process of dismantling a power scheme maintained through police misconduct.*

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## I. Introduction

Christopher Columbus had his sights set for India when he stumbled upon what is now the United States. Columbus proclaimed the territory officially “found,” negating the fact that an entire society and cultural fabric already existed. The subsequent colonization of the Native American population established cultural and ethnic hierarchies that subordinated Native Americans in favor of Eurocentric traditions and ideals.<sup>1</sup> As European imperial power continued to expand across the globe, Eurocentric ideologies prevailed.<sup>2</sup> The white European male with status and privilege encapsulated the image of power.

This power hierarchy was reinforced when slavery became an institution in the American colonies. Africans—as the sentiment went—were savage “others” who were inherently inferior to white colonists. Pseudo-science reaffirmed this conception by declaring Africans intellectually deficient and physically anomalous.<sup>3</sup> The racial dimension of this hierarchy served the colonists well because they could rationalize their sub-human treatment of slaves who effectively provided the labor and economic means for colonists’ survival.

Racial dimensions were not the sole construct for maintaining power. The colonial era illustrated multiple facets of subordinated identities, including gender. Women’s status occupied a low level on the spectrum of hierarchical identities. The “breeding slave”<sup>4</sup> exemplified women’s relegated position; these

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1 See generally Gayle K. Brunelle, *The World Economy and Colonial Expansion*, in 1 ENCYCLOPEDIA OF EUROPEAN SOCIAL HISTORY 461–74 (Peter N. Stearns ed., 2001).

2 *Id.*

3 See generally Rutledge M. Dennis, *Social Darwinism, Scientific Racism, and the Metaphysics of Race*, 64 J. NEGRO EDUC. 243 (1995) (tracing scientific racism from the early works of Darwin and Spencer to the intelligence testing movement led by Galton and Binet, in order to demonstrate that science has been used to justify proposing, projecting, and enacting racist policies); see also *Phrenology and “Scientific Racism” in the 19<sup>th</sup> Century*, WORDPRESS (Mar. 5, 2017), <https://pages.vassar.edu/realarchaeology/2017/03/05/phrenology-and-scientific-racism-in-the-19th-century/> (stating that “the pseudoscience of phrenology, the study of skull shapes as an indicator of mental abilities, . . . was used to prove prevalent yet baseless hypotheses about the inferiority of non-white races.”).

4 See generally STEPHEN ASHLEY, *THE BREEDING OF AMERICAN SLAVES: TRUE STORIES OF AMERICAN SLAVE BREEDING AND SLAVE BABIES* (2012).

female slaves were nothing more than sexual and reproductive commodities that could replenish a slaveholder's labor force.

The breeding slave exemplifies the early interplay of multiple identities. Not only did the breeding slave suffer because of race, but she also suffered because of her sex.<sup>5</sup> In 1989, legal scholar Kimberlé Crenshaw coined the term "intersectionality" to describe "the way multiple oppressions are experienced."<sup>6</sup> Crenshaw argued that forms of discrimination often did not fit into simple categories, such as racism *or* sexism.<sup>7</sup> Rather, a black woman may be discriminated against because of both racism *and* sexism.<sup>8</sup> Multiple identities, Crenshaw argued, coalesced into formulations of discrimination with undesigned parameters.<sup>9</sup>

Crenshaw's theory provides a telling story of who wields power in contemporary U.S. society, which suffers from the same power structures inherent during the era of colonization and colonial slavery. Today's power hierarchy places certain categories of people at the bottom, while further disempowering those with intersectional identities who are historically considered disadvantaged. The legacy of U.S. police misconduct demonstrates that low-income women of color are consistently placed on the bottom of today's power structure as a mechanism of social control; the police, who are supposed to be the very protectors of disenfranchised groups, reinforce a power hierarchy that enmeshes low-income women of color into a perpetual struggle for survival in an antagonistic system that consistently tries to remind them of their "place" in the power schematic. Adoption of human rights standards into binding law, particularly recognition of the American Declaration of the Rights and Duties of Man (hereinafter referred to as the "American Declaration" or "Declaration"), can begin the process of dismantling a power scheme riddled with human rights abuses.

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5 Please note that sex is separate from gender. Sex is biologically determined, while gender exists along a continuum. In this piece, I will only consider sex and will use the terms "sex" and "gender" interchangeably.

6 Sharon Smith, *Black Feminism and Intersectionality*, 91 INT'L SOCIALIST REV. (2013), <http://isreview.org/issue/91/black-feminism-and-intersectionality>.

7 Kimberlé Crenshaw, *Mapping the Margins: Intersectionality, Identity Politics, and Violence Against Women of Color*, 43 STAN. L. REV. 1241, 1243–44 (1990).

8 *Id.*

9 Kimberlé Crenshaw, *Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics*, 1989 U. CHI. LEGAL F. 139, 140 (1989).

In Section II of this paper, I will discuss how hegemonic masculinity permeates police culture, posing particular problems for low-income women of color. In Section III, I will consider problematic policing policies that disproportionately impact low-income women of color. These policies intensified throughout the War on Drugs and linger into the present; they include the use of *Terry* stops, the increased militarization in policing, and inequitable incarceration rates. Section IV will consider how recognition of international human rights norms, particularly the American Declaration, can operate to dismantle the deeply entrenched power hierarchy in the U.S. This analysis will largely consider the case of *Lenahan v. United States*, heard by the Inter-American Commission on Human Rights. Adopting the American Declaration provides recognition that police misconduct constitutes a human rights abuse that strips low-income women of color of their dignity, entrenching them in a constant state of victimization.

## II. Hegemonic Masculinity

“In a yearlong investigation of sexual misconduct by U.S. law enforcement . . . it was impossible to discern any . . . distinct patterns, other than a propensity for officers to use the power of their badge to prey on the vulnerable.”<sup>10</sup>

In the 1980s, a “sociological theory of gender,”<sup>11</sup> known as hegemonic masculinities theory, emerged. “The hegemonic pattern of masculinity is the definition of manhood that is dominant in a given cultural context.”<sup>12</sup> In the U.S., the hegemonic portrayal of masculinity is exemplified through positions of power that enable males to demonstrate machismo<sup>13</sup> through displays of domination and aggression.<sup>14</sup> These displays disproportionately affect racial minorities who are perceived as entities to be dominated<sup>15</sup> based

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10 Matt Sedensky, *Hundreds of Officers Lose Licenses over Sex Misconduct*, ASSOCIATED PRESS (Nov. 1, 2015), <https://apnews.com/fd1d4d05e561462a85abe50e7eaed4ec>.

11 R.W. Connell & James W. Messerschmidt, *Hegemonic Masculinity: Rethinking the Concept*, 19 GENDER & SOC'Y 829, 830 (2005).

12 Frank R. Cooper, “Who’s the Man?”: *Masculinities Studies, Terry Stops, and Police Training*, 18 COLUM. J. GENDER & L. 671, 672 n.5 (2009).

13 See generally *id.* (stating that police culture is deeply entrenched in machismo).

14 *Id.* at 677.

15 See generally *id.*

on their perceived inferiority. In addition, hegemonic masculinity seeks “to assert and maintain men’s societal dominance over women.”<sup>16</sup> The intersectionality of racial, economic, and gender identities results in police misconduct that disproportionately falls on low-income women of color.

In the U.S., policing culture provides an ideal forum for shows of masculinity. Professor Leigh Goodmark refers to police settings as emblematic of other male-dominated institutions, sharing characteristics such as “a need for dominance, an emphasis on masculine solidarity[,] . . . a focus on physical courage, and the glamorization of violence.”<sup>17</sup> Policing appeals to those with authoritarian personalities who can use violence as a means to assert their masculinity.<sup>18</sup> Not only does the profession appeal to those with greater inclinations towards generalized violence,<sup>19</sup> but it also perpetuates such violence. Studies reveal this perpetuation; Susan Miller found that police officer gatherings tend to revolve around topics that “reinforce[] the tough, masculine, crimefighting image of policing.”<sup>20</sup> Anastasia Prokos and Irene Padavic found that male officers in training academy used verbally derogatory and objectifying language toward women.<sup>21</sup> As such, the culture of policing bolsters hegemonic masculinity. U.S. policing has become a space where subordinated identities continue to exist through the victimization of low-income women of color.

### **A. Daniel Holtzclaw: Hegemonic Masculinity Manifested in Policing**

*“In my mind, all I could think of was he was going to shoot me, he was going to kill me . . . I kept begging, ‘Sir, don’t make me do this, don’t make me do this, sir. Please. You’re going to shoot me.’ All I could see was my life flashing before my eyes and the holster on his right side . . . All I can say is I was a*

16 Leigh Goodmark, *Hands Up at Home: Militarized Masculinity and Police Officers Who Commit Intimate Partner Abuse*, 2015 BYU L. REV. 1183, 1209 (2016).

17 *Id.* at 1210–11.

18 *Id.* at 1205–08.

19 *Cf. id.*

20 *Id.* at 1211 (quoting SUSAN L. MILLER, VICTIMS AS OFFENDERS: THE PARADOX OF WOMEN’S VIOLENCE IN RELATIONSHIPS 126, 175–76 (2005)).

21 *Id.* at 1212 (citing Anastasia Prokos & Irene Padavic, “There Oughtta Be a Law Against Bitches”: Masculinity Lessons in Police Academy Training, 9 GENDER, WORK, & ORG. 439, 439 (2002)).

*victim, I was traumatized, I went to therapy, I had a stroke behind this.*"<sup>22</sup>

–Jannie Ligons, Holtzclaw sexual assault victim

T.M., a drug user and sex worker, was at an apartment complex known for drugs, when she took note of a police officer.<sup>23</sup> The officer stopped her at approximately 9 p.m. as T.M. left the complex.<sup>24</sup> The officer directed her to get in the backseat of his patrol car and took her purse.<sup>25</sup> He drove two blocks before stopping to check for existing warrants and to search through T.M.'s purse, where he found a crack pipe.<sup>26</sup> T.M. was still seated in the backseat when the officer "got out of the car and exposed his erect penis to her. He 'made it very clear it's basically this or jail.'"<sup>27</sup>

The officer at issue, Daniel Holtzclaw, was convicted of raping and sexually victimizing eight black women in the same minority, low-income neighborhood.<sup>28</sup> In a show of masculinity, Holtzclaw exerted sexual domination over his victims. He used his position and authority as an officer to victimize low-income women of color. Holtzclaw's misconduct demonstrates the use of policing as a method to demonstrate masculinity; the culture of policing emboldens displays of aggression and domination that epitomize the hegemonic formulation of masculinity.

The reality of officers' power in policing is reiterated by a number of Holtzclaw's victims. The youngest of his victims said Holtzclaw discovered her outstanding warrant for trespassing,

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22 Michael Martinez & Jethro Mullen, *Victims Describe Assaults by Convicted Ex-Oklahoma City Cop Daniel Holtzclaw*, CNN (Dec. 11, 2015, 8:17 PM), <http://www.cnn.com/2015/12/11/us/oklahoma-daniel-holtzclaw-verdict/index.html>.

23 Jessica Testa, *How Police Caught the Cop who Allegedly Sexually Abused Black Women*, BUZZFEED (Sept. 5, 2014, 1:40 PM), [https://www.buzzfeed.com/jtes/daniel-holtzclaw-alleged-sexual-assault-oklahoma-city?utm\\_term=.ypQ6yBOWAq#.onQ2BOz8ne](https://www.buzzfeed.com/jtes/daniel-holtzclaw-alleged-sexual-assault-oklahoma-city?utm_term=.ypQ6yBOWAq#.onQ2BOz8ne).

24 *Id.*

25 *Id.*

26 *Id.*

27 *Id.*

28 Camila Domonoske, *Former Oklahoma City Police Officer Sentenced to 263 Years for Sexual Assaults*, NPR (Jan. 21, 2016, 4:38 PM), <http://www.npr.org/sections/thetwo-way/2016/01/21/463867164/former-oklahoma-city-police-officer-sentenced-to-263-years-for-sexual-assaults>; see also Jessica Lussenhop, *Daniel Holtzclaw Trial: Standing with 'Imperfect' Accusers*, BBC NEWS (Nov. 13, 2015), <http://www.bbc.com/news/magazine-34791191>.



offered her a ride while walking to her mother's house, and ultimately followed her to the front porch where Holtzclaw "touched her breasts and slid his hand into her panties before pulling off her shorts and raping her. When it was over, the teen said he told her he might be back to see her again."<sup>29</sup> Holtzclaw's actions speak to officers' presumed attribute of being "above the law." The victim demonstrated this belief at a pretrial hearing when expressing her feeling of hopelessness: "[W]hat am I going to do? Call the cops? He was a cop."<sup>30</sup> In the U.S., "officers' power, independence[,] . . . and engagement with those perceived as less credible combine to give cover to [police] predators;"<sup>31</sup> these traits place officers in a position ripe for abuse.

Policing culture that enforces and preserves masculinity serves as a constraint on society<sup>32</sup> that can be rectified through a global framework that reaches beyond national boundaries and biases. "The American Declaration asserts that its human rights provisions are not dependent on nationality but are universally guaranteed to everyone by virtue of being human."<sup>33</sup> It is such a universal approach to rights and human dignity that can begin to dismantle the U.S. caste system.<sup>34</sup>

### III. Problematic Policies in Policing

Beyond hegemonic masculinity, problematic policies in policing have further perpetuated a framework that works to keep low-income women of color on the lowest rungs of the societal ladder. The War on Drugs, declared by President Nixon

29 Sedensky & Merchant, *supra* note 10.

30 *Id.*

31 *Id.*

32 ANGELA M. WORKMAN-STARK, INCLUSIVE POLICING FROM THE INSIDE OUT 23 (2017) (stating that "[a]ttempts from male officers to maintain an image of hyper masculinity have led to excessive risk taking, poor-quality decisions, [and] the violation of civil and human rights . . . "); Marian Lief Palley, *Women's Rights as Human Rights: An International Perspective*, 515 ANNALS AM. ACAD. POL. & SOC. SCI. 163, 164 (1991).

33 *American Declaration on the Rights and Duties of Man*, LONDON SCH. OF ECON. (2016), <http://blogs.lse.ac.uk/vaw/regional/the-americas/the-american-declaration-on-the-rights-and-duties-of-man/>.

34 This is not to say that constitutional protections including the Fourth, Eighth, and Fourteenth Amendments do not serve as tremendous protections; I argue that adopting and accepting the American Declaration operates to supplement American law.



in 1971,<sup>35</sup> had longstanding implications for policing, as did the introduction of *Terry* stops in 1968.<sup>36</sup> The War on Drugs also resulted in increased militarization in policing, as well as growing incarceration rates that disproportionately impacted women of color.<sup>37</sup> These policing strategies have persisted into the current day and entrench low-income women of color into greater impoverishment and deprivation through difficulty in attaining and retaining employment, economic instability, drug dependency, and mental health effects that linger from trauma.<sup>38</sup>

### **A. *Terry Stops and the War on Drugs as Pretext for the War on Low-Income Women of Color***

President Nixon proclaimed that drug abuse was “public enemy number one.”<sup>39</sup> Subsequent presidents intensified their efforts to abolish the drug trade<sup>40</sup> and localities and state governments followed suit.<sup>41</sup>

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35 *War on Drugs: United States History*, ENCYCLOPEDIA BRITANNICA (2017), <https://www.britannica.com/topic/war-on-drugs>.

36 *See infra* section III.A.2.

37 *See infra* sections III.B, III.C.

38 *See generally* SARAH LYONS & NASTASSIA WALSH, A CAPITOL CONCERN: THE DISPROPORTIONATE IMPACT OF THE JUSTICE SYSTEM ON LOW-INCOME COMMUNITIES IN D.C., JUST. POL’Y INST. 1, 4 (2010) (accumulating evidence in the D.C. area that shows “people with the fewest financial resources are more likely to end up in prison or jail,” and “socio-economic status intersects with the criminal justice system” so that there are “decreased opportunities for success after conviction because of housing and job discrimination as well as other challenges [that] can trap individuals in poverty”); *see also* KAREN DOLAN & JODI L. CARR, THE POOR GET PRISON: THE ALARMING SPREAD OF THE CRIMINALIZATION OF POVERTY, INST. FOR POL’Y STUD. (2015) (finding that there are “38,000 collateral consequence statutes nationwide” for individuals with criminal convictions that result in “barriers to housing, employment, voting, and many public benefits” including ineligibility to “basic health, mental health . . . substance abuse and food assistance”).

39 *War on Drugs: United States History*, *supra* note 35.

40 *Timeline: America’s War on Drugs*, NPR (Apr. 2, 2007, 5:56 PM), <https://www.npr.org/templates/story/story.php?storyId=9252490> (outlining President Reagan’s Anti-Drug Abuse Act, President H.W. Bush’s creation of the Office of National Drug Control Policy, and President Clinton’s investment in drug abolishment, including \$1.3 billion to Plan Columbia).

41 *See generally* Hannah LF Cooper, *War on Drugs Policing and Police Brutality*, 50 SUBSTANCE USE & MISUSE 1188 (2015) (providing historical context between race and policing in the U.S. and reviewing erosions to the Fourth Amendment and Posse Comitatus Act—all of which helped establish policies for the War on Drugs).

Between 1982 and 2007, arrests for drug possession increased threefold and racial-ethnic distinctions in arrests emerged.<sup>42</sup> From 1976 to 1992, Black Americans accounted for about 12% of the population while White Americans accounted for approximately 82% of the population.<sup>43</sup> Despite this, Black Americans went from constituting 22% of drug-related offenses to 40%, while White Americans went from constituting 77% of these arrests to 59%;<sup>44</sup> this trend of increased drug-related offenses relative to population between the racial groups has continued<sup>45</sup> despite the fact that disparities in arrest patterns are not explained by differences in patterns of drug use.<sup>46</sup> The most recent national survey reveals “no statistically significant differences in the rates of current illicit drug use between 2012 and 2013 for any . . . racial/ethnic groups;”<sup>47</sup> “whites and blacks use drugs at almost exactly the same rates.”<sup>48</sup>

One of the greatest assets for police throughout the War on Drugs has been the ability to use *Terry* stops.<sup>49</sup> The subsequent analysis will consider the Supreme Court’s rationale in enabling *Terry* stops, and will further present the argument that the Court’s permission to allow such stops—though seemingly well-intended—has enabled and emboldened police to act with an impunity that did not exist prior to the holding. Police officers’ perception of their enhanced freedom, as provided by the highest court in the U.S., bolstered social control over communities of color, especially over low-income black women who found themselves subject to extreme police misconduct.

### 1. *Terry v. Ohio: The Introduction of “Stop and Frisk” Policing*

42 *Id.* at 1190.

43 *Id.*

44 *Id.*

45 Lauren Carroll, *How the War on Drugs Affected Incarceration Rates*, POLITIFACT (July 10, 2016, 6:27 PM), <http://www.politifact.com/truth-o-meter/statements/2016/jul/10/cory-booker/how-war-drugs-affected-incarceration-rates/>.

46 SUBSTANCE ABUSE AND MENTAL HEALTH SERV. ADMIN., DHHS 14-4863, RESULTS FROM THE 2013 NATIONAL SURVEY ON DRUG USE AND HEALTH: SUMMARY OF NATIONAL FINDINGS 26 (2013).

47 *Id.*

48 Graham Boyd, *The Drug War is the New Jim Crow*, ACLU (July 2001), <https://www.aclu.org/other/drug-war-new-jim-crow>.

49 See *infra* section III.A.1.

The 1968 Supreme Court Case, *Terry v. Ohio*, ruled on the constitutionality of colloquially-termed “stop and frisk” policing strategy.<sup>50</sup> In *Terry*, plain-clothes Officer McFadden was on duty and observed two men continuously walking up and down a stretch of the street while peering into the same storefront.<sup>51</sup> The men conferred with a third individual on two occasions.<sup>52</sup> McFadden, upon noting the suspicious behavior, approached the three men, identified himself as an officer, and after the men mumbled in response to his inquiries, “Officer McFadden grabbed petitioner Terry, spun him around so that he was facing the other two [petitioners] . . . and patted down the outside of his clothing.”<sup>53</sup> The Court emphasized that McFadden “did not put his hands beneath the outer garments of [the petitioner] until he felt [his] gun[.]”<sup>54</sup>

The case implicated the Fourth Amendment,<sup>55</sup> which provides that “[t]he right of the people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures, shall not be violated . . . .”<sup>56</sup> As such, citizens are “entitled to be free from unreasonable governmental intrusion.”<sup>57</sup> The Court acknowledged the indignity that arises from any stop, writing that a stop “is a serious intrusion upon the sanctity of the person.”<sup>58</sup> However, the Fourth Amendment protects against *unreasonable* search and seizure; an invasion of a civilian’s personal security as a result of a stop and frisk is only unreasonable<sup>59</sup> if it is (a) not “justified at its inception, [or (b) not] reasonably related in

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50 *Terry v. Ohio*, 392 U.S. 1 (1968).

51 *Id.* at 5–6.

52 *Id.* at 6.

53 *Id.* at 7.

54 *Id.*

55 The Fourth Amendment is made applicable to the states through the Fourteenth Amendment. *When the Fourth Amendment Applies*, FINDLAW, <http://criminal.findlaw.com/criminal-rights/when-the-fourth-amendment-applies.html> (last visited Apr. 3, 2018).

56 U.S. CONST. amend. IV.

57 *Terry*, 392 U.S. at 9.

58 *Id.* at 17.

59 Reasonableness must be measured through an objective standard, and any intrusion upon civilians must be justified through “specific and articulable facts.” *Id.* at 21.

scope<sup>60</sup> to the circumstances justifying the interference.”<sup>61</sup>

In *Terry*, the Court concluded that McFadden conducted a reasonable frisk because the scope of his frisk was limited and because he had reasonable cause to suspect that he was dealing with armed and dangerous individuals.<sup>62</sup> McFadden was “entitled for the protection of himself and others in the area to conduct a carefully limited search of the outer clothing . . . in an attempt to discover weapons which might be used to assault him.”<sup>63</sup>

Despite the Court’s holding that *Terry* stops must follow the parameters of reasonableness and limited scope, stop and frisk policing has resulted in police misconduct.<sup>64</sup> The Court’s declared constitutionality of *Terry* stops unlocked a door that enabled police to push the limits of lawful conduct.<sup>65</sup> Akin to the Black Codes of the Reconstruction Era and the Jim Crow laws of the Civil Rights Era, *Terry* stops became yet another tactic of social control that worked to enforce power hierarchies.<sup>66</sup> The War on Drugs posed an opportunity for increased use of stop and frisk policing; police concentrated their efforts on high drug trafficking areas that they largely affiliated with communities of color.<sup>67</sup> As the policing assault on communities of color increased, low-income black women found themselves subject to police misconduct, which reinforced the population’s low and marginalized status within the power hierarchy.<sup>68</sup>

In *Terry*, both petitioner’s counsel and the Court itself foreshadowed the possible consequences of the holding. Petitioner’s counsel argued for “strictly circumscribed” police

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60 The scope of a frisk must be different from the scope arising from an arrest in that the former should be limited to seeking and seizing a particular item. This limited search is ideally brief. *Id.* at 26.

61 *Id.* at 20.

62 *Id.* at 30.

63 *Terry*, 392 U.S. at 30.

64 See *infra* section III.A.2–3.

65 See *infra* section III.A.2–3.

66 See *infra* section III.A.2.; see also Cooper, *supra* note 41, at 1190.

67 Cooper, *supra* note 41, at 1191 (stating that participants in a study experienced stop and frisks as a form of psychological violence in which “officers identified hotspots (i.e., spaces where drug activity occurred) and viewed anyone walking through that space as a possible criminal”).

68 *Id.*; see generally LENORA LAPIDUS ET AL., CAUGHT IN THE NET: THE IMPACT OF DRUG POLICIES ON WOMEN AND FAMILIES, ACLU 1 (Mar. 2005).

authority,<sup>69</sup> and alleged that expanding police authority

would constitute an abdication of judicial control over, and indeed an encouragement of, substantial interference with liberty and personal security by police officers . . . . This, it is argued, can only serve to exacerbate police-community tensions in the crowded centers of our Nation's cities.<sup>70</sup>

The Court discussed the possibility of “lawless police conduct” and the “effect of legitimizing the [mis]conduct” by permitting evidence collected by *Terry* stops.<sup>71</sup> It also acknowledged the “intolerable intensity and scope”<sup>72</sup> of searches (frisks), all of which the Court deemed “serious intrusion[s] upon the sanctity of the person.”<sup>73</sup> The Court’s holding thus recognized the amount of power held by officers, whether exerted lawfully or not.

## 2. *Policing After Terry*

“The NYPD’s stop-and-frisk practices raise serious concerns over racial profiling, illegal stops and privacy rights. The Department’s own reports on its stop-and-frisk activity confirm what many people in communities of color across the city have long known: The police are stopping hundreds of thousands of law abiding New Yorkers every year, and the vast majority are black and Latino.”<sup>74</sup>

Residential segregation has long existed in the U.S., partly through the “linkage . . . between race, space, and policing.”<sup>75</sup> Segregated low-income black communities have been socially and politically created in order to preserve discriminatory racial practices; the construction of these communities has had a

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69 *Terry*, 392 U.S. at 25–26.

70 *Id.* at 12.

71 *Id.* at 12–13.

72 *Id.* at 18.

73 *Id.* at 17.

74 *Stop and Frisk Practices*, N.Y. CIV. LIBERTIES UNION (2017), <https://www.nyclu.org/en/issues/racial-justice/stop-and-frisk-practices>.

75 Sandra Bass, *Policing Space, Policing Race: Social Control Imperatives and Police Discretionary Decisions*, 28 SOC. JUST. 156, 158 (2001).

significant impact on policing in such spaces.<sup>76</sup> Though whites and minorities use and sell drugs at roughly the same rates,<sup>77</sup> black communities have disproportionately been targeted in the War on Drugs.<sup>78</sup> Between 2004 and 2009, one of the NYPD's top rationales for a stop was based on an area's designation as "high crime."<sup>79</sup> A great deal of these high-crime regions were black communities; "[r]ace was [a] lens through which drug problems in the United States were viewed, coloring both the definition of the problem and the proposed solutions."<sup>80</sup> The "proposed solutions" included increased zealotry in stop and frisk policing, with stops becoming largely normalized in low-income black neighborhoods.<sup>81</sup>

The War on Drugs has consistently forced many low-income women of color to defend themselves against *Terry* stops. "Existing research shows that women of all races use illegal drugs at roughly the same rate, [but] the widespread use of race as a basis for more frequent and more intrusive police stops and searches of women of color in the context of the war on drugs is all too common."<sup>82</sup> Though these stops may unconstitutionally be based on racial profiling, the Supreme Court has not yet overturned *Terry* stops as a mechanism to preclude this police behavior. This is despite a case out of the Southern District of New York that held that the city unconstitutionally used racial profiling in its stop and frisk policing—an equal protection violation.<sup>83</sup>

Both *Terry* stops and the War on Drugs serve as pretext to socially controlling the existing hierarchy that places low-income women of color on the lower rungs of power.<sup>84</sup> Low-income women

76 *Id.* at 157–58.

77 WAR COMES HOME: THE EXCESSIVE MILITARIZATION IN AMERICAN POLICING, ACLU 1, 95 n.102 (June 2014) [hereinafter WAR COMES HOME].

78 "Socioeconomic inequality leads people of color to disproportionately use and sell drugs outdoors, where they are more readily apprehended by police." Nazgol Ghandnoosh, *Black Lives Matter: Eliminating Racial Inequality in the Criminal Justice System*, THE SENTENCING PROJECT 1, 14 (Feb. 2015).

79 *Floyd v. City of New York*, 959 F. Supp. 2d 540, 574 (S.D.N.Y. 2013).

80 Jamie Fellner, *Race, Drugs, and Law Enforcement in the United States*, 20 STANFORD L. & POL'Y REV. 257, 263 (2009).

81 *Cf. id.* at 270–71.

82 LAPIDUS ET AL., *supra* note 68, at 30–31.

83 *See generally Floyd*, 959 F. Supp. 2d at 574.

84 *Cf. Philip M. Stinson et al., Police Sexual Misconduct: A National Scale Study of Arrested Officers*, 30 CRIM. JUST. FAC. PUBL'NS 1, 6 (2014) (referencing Walker and Irlbeck's 2002 study that refers to the problem of "'driving while female,' wherein police use the pretext of alleged traffic violations to sexually



of color, when stopped by police, may want the problem to “go away.”<sup>85</sup> They often cannot afford a criminal conviction or arrest; they may not be able to pay fines or bonds or have difficulty getting a job with a listed conviction; they may become ineligible for public benefits or lose the right to parole; they may be single mothers who can potentially lose custody of their children.<sup>86</sup> The War on Drugs and *Terry* stops work in concert with one another to prey on these vulnerabilities.<sup>87</sup> Low-income women of color, upon being stopped by police and found in possession of drugs, may opt for a conviction that will further spiral them into poverty or may agree to so-called quid pro quo sexual favors.<sup>88</sup> Both “options” speak to police misconduct, whether through racial profiling or sexual abuse.

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harass or abuse female drivers”).

- 85 See, e.g., Alene Tchekmedyan, *Women who Alleged Sexual Assault by 2 LAPD Officers Testify: ‘I Didn’t Really Feel Like I had a Choice,’* L.A. TIMES (Nov. 8, 2016, 3:00 AM) <http://www.latimes.com/local/lanow/la-me-ln-lapd-officers-rape-charges-20161108-story.html> (stating that one woman had sex in the backseat of a police car in order to avoid staying in jail; another had sex with officers to “earn points” to get a pending drug charge dropped”).
- 86 See generally Crenshaw, *supra* note 7, at 1245 (stating that “[m]any women of color . . . are burdened by poverty, child care responsibilities, and the lack of job skills”); see also Amy L. Solomon, *In Search of a Job: Criminal Records as Barriers to Employment*, NAT’L INST. OF JUST. 44 (June 15, 2012), <https://www.nij.gov/journals/270/pages/criminal-records.aspx> (stating that the burdens placed upon low-income women of color are exacerbated by an arrest record, which results in “collateral consequences [that] create additional barriers”); see also Rebecca M. Loya, *The Role of Sexual Violence in Creating and Maintaining Economic Insecurity Among Asset-Poor Women of Color*, 20 VIOLENCE AGAINST WOMEN 1299, 1300 (2014) (stating that “sexual assault has devastating physical, psychological, and behavioral consequences that can diminish labor market performance, disrupt earnings, and create economic instability for survivors who lack access to assets. Women of color face particular risk”); see also LAPIDUS ET AL., *supra* note 68, at 56.
- 87 See generally LAPIDUS ET AL., *supra* note 68 (executive summary stating that “[f]ederal and state drug laws and policies over the past twenty years have had specific, devastating, and disparate effects on women, and particularly on women of color and low-income women”).
- 88 Stinson et al., *supra* note 84, at 4; cf. Tchekmedyan, *supra* note 85. Daniel Holtzclaw, for example, utilized such quid pro quo sexual favors, implying to some of his victims that he “would help them with their cases [of drug possession] if they performed sexual acts.” Jessica Lussenhop, *Daniel Holtzclaw Trial: Standing with ‘Imperfect’ Accusers*, BBC NEWS (Nov. 13, 2015), <http://www.bbc.com/news/magazine-34791191>.

### 3. *Limitations in U.S. Law*

Though the Fourth Amendment is meant to protect individuals from unreasonable search and seizure, the Court's precedent in *Terry* resulted in newfound authority and power for officers. Effectively, the Court abdicated judicial control over police. The Court also alluded to difficulty in controlling police misconduct through law and judicial authority:

Doubtless some police "field interrogation" conduct violates the Fourth Amendment. But a stern refusal by this Court to condone such activity does not necessarily render it responsive to the exclusionary rule. Regardless of how effective the rule may be where obtaining convictions is an important objective of the police, *it [the Court] is powerless to deter invasions of constitutionally guaranteed rights* where the police either have no interest in prosecuting or are willing to forgo successful prosecution in the interest of serving some other goal.<sup>89</sup>

The Court's acknowledgment of limitations in curtailing police misconduct that fundamentally abridged civilians' constitutionally protected rights demonstrates restrictions in U.S. law. Use of the War on Drugs to justify highly invasive *Terry* stops has significantly eroded the Fourth Amendment protection against unreasonable search and seizure. These stops are a human rights abuse that are best addressed through international law, which will be discussed in Section IV.

### **B. *Increased Militarization in Policing***

The Posse Comitatus Act of 1878 was passed to limit military interference in civilian policing.<sup>90</sup> In 1981, against the backdrop of the War on Drugs, Congress moved "to increase the amount of cooperation between the military and civilian law enforcement authorities as part of the 1982 Department of Defense Authorization Act."<sup>91</sup> Subsequent amendments and legislative

89 *Terry v. Ohio*, 392 U.S. 1, 13–14 (1968) (emphasis added). Here, the Court specifically referred to the exclusionary rule, which prohibits improperly gathered evidence from coming into court. *Id.*

90 Cooper, *supra* note 41, at 1192.

91 Commander Gary Felicetti & Lieutenant John Luce, *The Posse Comitatus Act*:



action increased this collaboration,<sup>92</sup> which had major ripple effects for low-income women of color.<sup>93</sup>

“SWAT [Special Weapons and Tactics team] was created to deal with emergency situations such as hostage, barricade and active shooter scenarios.”<sup>94</sup> As the Posse Comitatus Act lost relevance through Congressional exceptions, SWAT became increasingly deployed for domestic drug searches.<sup>95</sup> The expanded collaboration between domestic policing and SWAT—a unit of personnel that uses military-grade weapons—increased police power and authority. As such, police, akin to their increased rights under *Terry*, could once again expand their exertion of authority. Lack of local, state, and federal oversight, a dearth of standards for SWAT deployment, and the general “warrior mentality” that accompanies the militarization of policing, are sufficient factors to predict misconduct.<sup>96</sup> However, ignoring the dimensions of race, socioeconomics, and sex provides an incomplete narrative for exploring increased militarization in policing.

SWAT teams are required to serve a drug warrant to enter homes on the suspicion of drug possession.<sup>97</sup> Depending on the race of the target search warrant, there is a noticeable difference in the use of SWAT teams for warrants.<sup>98</sup> An ACLU investigation demonstrated that minority groups, including blacks and Latinos, are more likely to be targeted for drug warrants,<sup>99</sup> and a compilation through ProjectKnow, a drug addiction resource

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*Setting the Record Straight on 124 Years of Mischief and Misunderstanding Before Any More Damage is Done*, 175 MIL. L. REV. 86, 150 (2003).

92 See generally *id.* (outlining the history and evolution of the Posse Comitatus Act); see also Cooper, *supra* note 41, at 1192.

93 See *infra* section III.C.

94 WAR COMES HOME, *supra* note 77, at 2.

95 *Id.* at 5. See generally Sean J. Kealy, *Reexamining the Posse Comitatus Act: Toward a Right to Civil Law Enforcement*, 21 YALE L. & POL'Y REV. 383 (2003); see also Clyde Haberman, *The Rise of the SWAT Team in American Policing*, N.Y. TIMES (Sept. 7, 2014), <https://www.nytimes.com/2014/09/08/us/the-rise-of-the-swat-team-in-american-policing.html>.

96 WAR COMES HOME, *supra* note 77, at 3, 28–29, 32.

97 The Fourth Amendment protects against “unreasonable searches and seizures.” U.S. CONST. amend. IV. “[S]earches and seizures inside a home without a warrant are presumptively unreasonable.” *Payton v. N.Y.*, 445 U.S. 573, 586 (1980). However, there are two exceptions to the warrant requirement for searches of the home: (1) emergency and (2) exigency. *United States v. Martinez*, 403 F.3d 1160, 1163 (9th Cir. 2005).

98 WAR COMES HOME, *supra* note 77, at 36.

99 *Id.* at 35.

center, revealed a correlation between drug-related arrests and neighborhood poverty levels.<sup>100</sup> The use of militarized policing has exerted tremendous levels of power over low-income families of color, who have become increasingly subject to military force within their own homes. Not only do these families have to fear military intrusion into their homes based on their race and economic status, but they also do not have the right to notice when a SWAT team is deployed to execute a search warrant.<sup>101</sup> Lacking a right to notice arose from the Supreme Court's holding in *Hudson v. Michigan*. The Court held that notice was not required when deploying SWAT teams so long as a search warrant was used.<sup>102</sup> The *Hudson* decision was important because it permitted military-style invasion into private homes without notice and further diminished Fourth Amendment protections.<sup>103</sup>

"No-knock warrants [in which SWAT teams enter homes without knocking] were used (or probably used) in about 60 percent of the incidents in which SWAT teams were searching for drugs, even though many resulted in the SWAT team finding no drugs or small quantities of drugs."<sup>104</sup> This confounds the racial profiling tactics in policing because no-knock warrants expose communities of color with a secondary blow; these communities now face the threat of military response in their homes without warning. Increased militarization in policing therefore reinforces the existing power structure that "allow[s] us to view poor people of color trapped in ghettos as 'others,' unworthy of [the power elite's] care and concern."<sup>105</sup> The allowance of no-knock warrants further suppresses the rights of low-income communities of color that are commonly stereotyped as existing in a perpetual state of crime. Gender exacerbates the problem of police militarization

100 German Lopez, *These Maps Show the War on Drugs is Mostly Fought in Poor Neighborhoods*, VOX (Apr. 16, 2015, 2:10 PM), <https://www.vox.com/2015/4/16/8431283/drug-war-poverty>.

101 See *Hudson v. Michigan*, 547 U.S. 586, 594 (2006) (stating that the exclusionary rule could not be used for evidence obtained after a knock-and-announce violation; this decision allowed military-style invasion into citizens' homes without warning and further eroded constitutional protection through the Fourth Amendment).

102 *Id.* at 590.

103 See generally *id.*

104 WAR COMES HOME, *supra* note 77, at 33.

105 Michelle Alexander, *Obama's Drug War*, THE NATION (Dec. 9, 2010), <https://www.thenation.com/article/obamas-drug-war/>.

in low-income communities of color.<sup>106</sup> Because women have increasingly taken the role of sole caretakers for their children,<sup>107</sup> the militarization in policing may prompt greater family disunity through accidental deaths that funnel youth into the child welfare system.

The Court's allowance of expanded police powers under *Hudson* speaks to the limits of Fourth Amendment protections. The Court's interpretation of the Fourth Amendment's Warrant Clause maintains police control over low-income communities of color so that even militarized and aggressive policing tactics are legally sanctioned. SWAT officers are further protected by qualified immunity, making it nearly impossible to seek justice against harms resulting from their conduct.<sup>108</sup>

### C. Incarceration

The punitive penalties established for drug possession, combined with profiling low-income neighborhoods of color with military aggression, increased prison numbers exponentially.<sup>109</sup> Black individuals are 3.6 times more likely to be arrested for selling drugs and 2.5 times more likely to be arrested for possession than their white counterparts.<sup>110</sup> Arrests have a ripple effect that correlate with increased incarceration for the black population;<sup>111</sup> data also shows that the “incarcerated population is

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106 Cf. Anannya Bhattacharjee, *Whose Safety? Women of Color and the Violence of Law Enforcement*, JUST. VISIONS WORKING PAPER 1, 19–25 (2001).

107 Sarah Jane Glynn, *Breadwinning Mothers are Increasingly the U.S. Norm*, CTR. FOR AM. PROGRESS (Dec. 19, 2016), <https://www.americanprogress.org/issues/women/reports/2016/12/19/295203/breadwinning-mothers-are-increasingly-the-u-s-norm/> (stating that “from 1974 to 2015, the rate of families with children headed by a single mother nearly doubled—from 14.6 percent to 26.4 percent—while the rate of single fatherhood . . . [rose from] 1.4 percent to 8.1 percent,” far less than the rate of single motherhood).

108 WAR COMES HOME, *supra* note 77, at 93 n.59.

109 See generally Lapidus et al., *supra* note 68; see also Carroll, *supra* note 45 (stating that “[t]he state and federal prison population grew from 218,466 in 1974 to 1,508,636 in 2014, which is a nearly 600 percent increase. For comparison, the overall United States population has increased just 51 percent since 1974 . . . . In 1980, about 41,000 people were incarcerated for drug crimes . . . . In 2014, that number was about 488,400 — a 1,000 percent increase . . . . More people are admitted to prisons for drug crimes each year than either violent or property crimes”).

110 Carroll, *supra* note 45.

111 Nearly 60% of all sentenced inmates in 2013 were black or Hispanic despite the fact that the two groups make up about 30% of the total population. *Id.*

disproportionately poor.”<sup>112</sup>

For low-income black women with children, the excessive militarization and subsequent incarceration of their partners has left them at greater vulnerability of becoming sole caretakers.<sup>113</sup> As they are forced to unilaterally and unexpectedly provide for their families, low-income black women are likely plunged into “asset poverty,” which can “be understood as an income-dependent state, in which one has no economic or social safety net in the case of lost income or emergency expenses.”<sup>114</sup> For some, this may result in psychological consequences from stress and anxiety.<sup>115</sup> As pressure mounts, low-income black women find themselves consistently pushed to the bottom rungs of the power hierarchy through a series of factors including lack of economic power.<sup>116</sup>

Beyond isolating low-income women as sole caretakers, the excessive force and use of militarized tactics in policing has resulted in disproportionate incarceration of low-income black women.<sup>117</sup> “Between 1986 and 1999, the number of women incarcerated in state facilities for drug-related offenses increased by 888% . . . . [A]vailable research in these areas indicates a strong connection between women’s experiences of violence and economic and social pressures, and women’s drug use or involvement in the drug trade.”<sup>118</sup> Research also indicates that prisons perpetuate violence towards women because “[s]exual and physical violence against women at the hands of correctional officers is widespread

112 *Id.* (stating that “[t]he Prison Policy Initiative analyzed [a] survey and ‘found that incarcerated people had a median annual income of \$19,185 prior to incarceration, which is 41 percent less than non-incarcerated people of similar ages.’”).

113 “Incarcerated parents are overwhelmingly male—93% of parents in prison are men.” LAPIDUS ET AL., *supra* note 68, at 50.

114 Rebecca M. Loya, *The Role of Sexual Violence in Creating and Maintaining Economic Insecurity Among Asset-Poor Women of Color*, 20 VIOLENCE AGAINST WOMEN 1299, 1301 (2014).

115 *Cf.* Kien Hoe Ng et al., *The Global Economic Crisis: Effects on Mental Health and What Can Be Done*, 106 J. ROYAL SOC’Y MED. 211, 211 (2013) (stating that “[l]ongitudinal data show that financial difficulties lead to increased major depression”).

116 *See generally* LYONS & WALSH, *supra* note 38 (considering the negative trickle-down effects of low socioeconomic status); *see also* LAPIDUS ET AL., *supra* note 68 (writing about the vicious cycle of engaging in petty drug sales, drug use, and incarceration).

117 *See generally* LAPIDUS ET AL., *supra* note 68.

118 *Id.* at Executive Summary.

in United States prisons.”<sup>119</sup>

Incarceration has ripple effects on subsequent generations that negatively impacts communities of color. From 1991 through 1999, “African American children were nine times more likely to have a parent incarcerated than white children, [while] Latino children were three times as likely as non-Latino white children to have an incarcerated parent.”<sup>120</sup> While children with incarcerated fathers tend to receive care from other family members, those with incarcerated mothers tend to be placed in foster care.<sup>121</sup> This gendered trend intersects with class and race because more than half of those waiting to be adopted are black, though they are the least likely to be adopted.<sup>122</sup> Additionally, the likelihood of entering the child welfare system is greater for “[c]hildren from families receiving public assistance prior to parental conviction.”<sup>123</sup> As such, low-income children of color who become displaced through their mothers’ incarceration are primed for a life of displacement vis-à-vis the foster system.<sup>124</sup> Not only are children negatively impacted by these disproportionate incarceration rates, but mothers may “face emotional trauma due to separation from their children and frequently suffer from depression, loneliness, and despair.”<sup>125</sup> The effects can be even more pronounced for some subpopulations of this group; for instance, “[i]nfliction of such trauma on women with substance abuse problems is particularly problematic because these conditions often trigger the urge to use drugs”—further entrenching low-income women of color into inferior positions in

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119 *Id.*

120 *Id.*

121 *Id.* at 50.

122 *Id.*

123 *Id.*

124 Under the 1997 Adoption and Safe Families Act (ASFA), “states are required to initiate the termination of parental rights (TPR) proceedings when a child has been placed in foster care for 15 out of the last 22 months. A Government Accounting Office (GAO) report concluded that the combination of the Act’s 15-month foster care time limit and the median prison sentence for women (60 months) leaves the parental rights of thousands of mothers in jeopardy. Because 72% of all women in federal prisons are incarcerated for non-violent drug offenses, the expansive use of mandatory minimum sentences for these offenses seriously impacts the likelihood of termination of parental rights and contributes significantly to the rising number of children in the child welfare system.” *Id.* at 55 (citing U.S. GEN. ACCT. OFFICE, WOMEN IN PRISON: ISSUES AND CHALLENGES CONFRONTING U.S. CORRECTIONAL SYSTEMS (Dec. 1999)).

125 *Id.* at Executive Summary.

the social hierarchy.<sup>126</sup>

Given the disproportionate incarceration of low-income women of color, in combination with the violence in U.S. prisons, social hierarchy perpetuates itself through a cycle of skewed policing, disparate incarceration rates, and potential new trauma that can have long-lasting mental and physical health effects that cripple the ability for economic self-sufficiency and exacerbate drug dependency.<sup>127</sup>

#### IV. Using International Human Rights as a Method to Deconstruct Social Hierarchies

The police misconduct that works against low-income women of color operates as a form of gender-based violence. According to the Inter-American Commission on Human Rights, “gender-based violence is one of the most extreme and pervasive forms of discrimination.”<sup>128</sup> “The prohibition against gender-based discrimination is not only contained in numerous universal and global human rights treaties, it is also a part of customary international law which binds all States.”<sup>129</sup> The 1993 Declaration on the Elimination of Violence against Women states that “violence against women is one of the crucial social mechanisms by which women are forced into a subordinate position compared with men.”<sup>130</sup> Importantly, this subordinated position is exacerbated by intersectional identities.<sup>131</sup>

International law has been utilized for redress in cases of police misconduct.<sup>132</sup> Justin Hansford, a professor of law and a

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126 *Id.*

127 “Women abused in prison are likely to have long-term psychological scars, including Post Traumatic Stress Disorder (PTSD), Rape Trauma Syndrome, and ongoing fear, nightmares, and flashbacks, contributing to self-hatred, substance abuse, anxiety, depression, and suicide. . . . Women in prison who are sexually assaulted are exposed to sexually transmitted diseases.” *Id.* at 48.

128 *Lenahan v. United States*, Case 12.626, Inter-Am. Comm’n H.R., Report No. 80/11, ¶ 110 (2011).

129 LISA GORMLEY, *WOMEN’S ACCESS TO JUSTICE FOR GENDER-BASED VIOLENCE: A PRACTITIONER’S GUIDE NO.12* 18 (Int’l Commission of Jurists, 2016).

130 G.A. Res. 48/104 (Dec. 20, 1993).

131 *See supra* Parts I, II.

132 *See generally Lenahan*, Case 12.626; *see also* FAMILY OF MICHAEL BROWN ET AL., *UNITED STATES’ COMPLIANCE WITH THE CONVENTION AGAINST TORTURE AND OTHER CRUEL, UNHUMAN OR DEGRADING TREATMENT OR PUNISHMENT: WRITTEN STATEMENT ON THE POLICE SHOOTING*



human rights activist, worked with a contingency in Ferguson, Missouri after the death of Michael Brown.<sup>133</sup> “Frustrated by attempts to obtain justice at the local, state, and federal levels, and given the ongoing display of excessive force by a militarized police, Mike Brown Jr.’s family and several community organizations from St. Louis submitted a written statement to the U.N. CAT (Committee Against Torture) and traveled to Geneva to testify before the Committee during its review of the United States in November 2014.”<sup>134</sup> Hansford, in speaking about the complaint before the CAT, proclaimed that Brown’s death was

[a] human rights issue, not a civil rights issue, [that] black people need to take to the U.N. so that the world court—the court of public opinion throughout the world—could be the place where [black people] held [their] reckoning on whether or not race in America is something that is being approached from a place of justice or injustice.<sup>135</sup>

Hansford also noted that Brown’s killing was not about a single death or a single officer, but rather demonstrated a larger problem in the global movement:

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OF MICHAEL BROWN AND ENSUING POLICE VIOLENCE AGAINST PROTESTORS IN FERGUSON, MISSOURI 6–7 (2014) (claiming that police brutality in Ferguson, Missouri after the death of Michael Brown constituted a human rights violation under the Convention against Torture).

133 Justin Hansford & Meena Jagannath, *Ferguson to Geneva: Using the Human Rights Framework to Push Forward a Vision for Racial Justice in the United States After Ferguson*, 12 HASTINGS RACE & POVERTY L.J. 121 (2015). In August 2014, white officer Darren Wilson fatally shot eighteen-year-old black male Michael Brown. Autopsy reports revealed that Brown was shot six times, though it was inconclusive whether Brown’s hands were up in surrender or up in an “aggressive posture.” A grand jury did not bring criminal charges against Wilson, who resigned from the police department. The grand jury decision sparked widespread outrage and a series of protests across the nation. Monica Davey & Julie Bosman, *Protests Flare After Ferguson Police Officer Is Not Indicted*, N.Y. TIMES (Nov. 24, 2014), <https://www.nytimes.com/2014/11/25/us/ferguson-darren-wilson-shooting-michael-brown-grand-jury.html>; see also Joshua Barajas, *What Does Michael Brown’s Official Autopsy Report Actually Reveal?*, PBS (Oct. 23, 2014, 6:47 PM), <http://www.pbs.org/newshour/rundown/michael-browns-official-autopsy-report-actually-reveal/>.

134 Hansford & Jagannath, *supra* note 133, at 125.

135 Justin Hansford: *From Ferguson to Geneva*, YOUTUBE 10:07–10:34 (Aug. 10, 2015), <https://www.youtube.com/watch?v=jvybND2KnUc>.

[In apartheid South Africa] people from around the world [were] stand[ing] up on [black people's] behalf; they had to do that because internally, the politics were unmovable. So [people] had to go *outside* the country to get the power they needed to [effectuate] real change . . . . We are in the same exact position, domestically, in the United States.<sup>136</sup>

Hansford speaks to changing domestic police force against people of color by utilizing international agencies and law. However, the response to Brown's death also demonstrates an important bias in the U.S. power hierarchy. The names of Oscar Grant, Philando Castile, Eric Garner, Alton Sterling, Freddie Gray, and Tamir Rice are highly recognizable; all were black men who died at the hands of police. But what of the unjust killings of low-income women of color? In 1999, an officer shot Margaret LaVerne Mitchell—an elderly and homeless woman—in the back.<sup>137</sup> Though the shooting violated Los Angeles Police Department rules, the officer was acquitted of criminal charges.<sup>138</sup> In 2014, police shot 22 year-old Gabriella Nevarez in the back, chest, and thigh after she sped off with her grandmother's car and allegedly attempted to evade police by ramming into a patrol car.<sup>139</sup> A witness account stated that Nevarez tried to surrender when police opened fire, releasing 14 bullets.<sup>140</sup> Both officers involved were placed on temporary administrative leave;<sup>141</sup> a 2017 article from Nevarez's locality stated that "all but three of the fourteen [city] officers involved in fatal shootings since 2010 remain on the force."<sup>142</sup>

136 *Id.* at 12:13–12:33.

137 KIMBERLÉ CRENSHAW ET AL., *SAY HER NAME: RESISTING POLICE BRUTALITY AGAINST BLACK WOMEN* 13 (Afr. Am. Pol'y F. ed. 2015).

138 *Id.*

139 Ian McDonald, *Grandmother of Woman Shot by Police Speaks Out*, FOX (Mar. 9, 2014, 2:07 PM), <http://fox40.com/2014/03/09/grandmother-of-woman-shot-by-police-speaks-out/>; see also Cynthia Hubert et al., *Here are the People Fatally Shot by Police*, THE SACRAMENTO BEE (Mar. 12, 2017, 4:00 AM), <http://www.sacbee.com/news/local/crime/article137805493.html>.

140 Ian McDonald, *Grandmother of Woman Shot by Police Speaks Out*, FOX (Mar. 9, 2014), <http://fox40.com/2014/03/09/grandmother-of-woman-shot-by-police-speaks-out/>.

141 *Id.*

142 Anita Chabria, *Citrus Heights Police: Too Quick to Shoot?*, THE SACRAMENTO BEE (Mar. 12, 2017, 4:00 AM), <http://www.sacbee.com/news/local/crime/>



The deaths of Margaret LaVerne Mitchell and Gabriella Nevarez demonstrate that low-income women of color are brutalized and killed by police, though their deaths often go unnoticed. As Hansford notes, the international community is a forum to shed light on these human rights abuses that have been consistently ignored by the U.S.<sup>143</sup> Not only does international law provide voice to the voiceless, but it exerts pressure on governments to change their wrongful operating mechanisms.

U.S. police brutality is not a new phenomenon. The U.N. Human Rights Committee found the U.S.'s 2011 efforts to curtail police brutality lacking and "called on the United States to '[s]tep up its efforts to prevent the excessive use of force by law enforcement officers . . .'"<sup>144</sup> Issuing its concluding observations in August 2014, the U.N. Committee on the Elimination of Racial Discrimination recognized that "the U.S. government [needed] to go further in its efforts, especially with respect to investigating every complaint of excessive use of force by law enforcement, improving oversight and reporting, and providing additional details on the outcomes of the investigations."<sup>145</sup>

Despite providing a platform to air grievances and providing world recognition of its police forces' brutality, the world stage has not proven sufficient for changing the nature of U.S. policing. U.S. ambivalence to international law and agencies is exacerbated by the fact that the U.S. is not party to a number of international treaties and protocols, and has historically been unresponsive to U.N. advisory opinions or international agency decisions.<sup>146</sup> In order to

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article137804533.html.

143 See generally Hansford & Jagannath, *supra* note 133.

144 *Id.* at 141 (citing U.N. Hum. Rts. Comm., *Concluding Observations on the Fourth Periodic Report of the United States of America*, ¶11, U.N. Doc. CCPR/C/USA/CO/4 (Apr. 23, 2014)).

145 *Id.* at 141–42 (citing U.N. Comm. on the Elimination of Racial Discrimination, *Concluding Observations on the Combined Seventh to Ninth Periodic Reports of United States of America*, ¶ 8, U.N. Doc. CERD/C/USA/CO/7-9 (Aug. 29, 2014)).

146 See generally *Vienna Convention on Consular Relations (Paraguay v. United States of America)*, *Provisional Measures*, order on 9 Apr. 1998, I.C.J. Rep. 1998 (holding that Paraguayan national Breard's rights were violated under the Vienna Convention because the Paraguayan consulate was not notified of Breard's impending U.S. trial, nor was Breard provided with representation through the consulate. The ICJ issued a provisional order to halt Breard's execution in Virginia pending its final decision, but Breard was executed despite the provisional measure); see also Memorandum from President George W. Bush to the Attorney General (Feb. 28, 2005) (stating that the Vienna Convention

effectuate tangible change, the U.S. must (1) accept human rights norms as treaties having the force of binding law, and (2) adopt particular human rights norms into domestic law. This would not only pressure the U.S. government into responsiveness toward human rights abuses, but would also create a structure of domestic law that prompts internal momentum to dismantle the American caste system that disproportionately impacts low-income women of color. The adoption of human rights norms into domestic law would operate to supplement already-existing law and would strengthen human rights in the United States. In particular, the U.S. should adopt the American Declaration.

#### **A. *The American Declaration of the Rights and Duties of Man***

The American Declaration was adopted in Bogota, Columbia in 1948 at the same time that the Charter of the Organization of American States (OAS) was adopted.<sup>147</sup> The American Declaration served as “the first international (regional) human rights instrument of the modern era, adopted more than six months before the Universal Declaration of Human Rights.”<sup>148</sup> Eleven years after adopting the American Declaration, OAS member states approved the Inter-American Commission’s statute, which explicitly referenced the American Declaration in defining “human rights.”<sup>149</sup> Among other tasks, the Inter-American Commission on Human Rights (“IACHR” or “Commission”) “receives and decides complaints (“petitions”)

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does not create judicially enforceable rights that can be enforced in domestic courts, and subsequently withdrawing the U.S. from ICJ jurisdiction); see also *Medellín v. Texas*, 552 U.S. 491 (2008) (Supreme Court reversing the presumption that treaties are self-executing, which is at odds with the Supremacy Clause of the U.S. Constitution). Note also that the U.S. has not ratified the Rome Statute, which provides jurisdiction to the International Criminal Court (ICC), nor is the U.S. party to the United Nations Convention on the Law of the Sea (UNCLOS) or the American Convention on Human Rights, which provides jurisdiction to the Inter-American Court of Human Rights. Relevant also is that the U.S. has not ratified the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW).

147 Cecilia Cristina Naddeo, *The Inter-American System of Human Rights: A Research Guide*, THE HAUSER GLOBAL L. SCH. PROGRAM (Sept. 2010), [http://www.nyulawglobal.org/globalex/Inter\\_American\\_Human\\_Rights.html#americdecla](http://www.nyulawglobal.org/globalex/Inter_American_Human_Rights.html#americdecla). Thirty-five countries have ratified the OAS Charter, including the U.S. *OAS Member States*, OAS (Mar. 15, 2017), [http://www.oas.org/en/member\\_states/default.asp](http://www.oas.org/en/member_states/default.asp).

148 *Id.* § 2.1.

149 *Id.*

brought by individuals against States for alleged human rights violations.”<sup>150</sup> Eventually, the IACHR was incorporated into the OAS Charter; because the American Declaration governed the IACHR, the Declaration “implicitly [became] a key part of the binding Charter.”<sup>151</sup> Regardless, some States, including the U.S., argued that the American Declaration was not legally binding since it never took the form of a treaty with binding legal force.<sup>152</sup> This is aligned with U.S. ambivalence towards international law, despite the fact that Supreme Court case law, including *Roper v. Simmons* and *Lawrence v. Texas*, cite to international human rights frameworks.<sup>153</sup> Given general reluctance to acknowledge the legally binding nature of international law and the American Declaration, accepting the Declaration as a treaty with binding force and incorporating it into U.S. domestic law would sidestep arguments against its enforcement as a major human rights document that can prompt the dismantling of social hierarchies.

**B. Applying the American Declaration: Jessica Lenahan v. United States**

“The petitioners contend that Jessica Lenahan’s claims are paradigmatic of those of numerous . . . victims in the United States, the majority of which are *women* and children, who pertain disproportionately to *racial and ethnic minorities and to low-income groups*.”<sup>154</sup>

In 2005, the U.S. Supreme Court heard the case of Jessica

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150 *Video Guide—Addressing Human Rights Violations in the Americas: Advocacy Before the Inter-American System*, INT’L. J. RES. CNTR., <http://ijrcenter.org/wp-content/uploads/2014/04/Video-Guide.pdf>.

151 Naddeo, *supra* note 147.

152 *Id.*

153 Adam Liptak, *U.S. Court is Now Guiding Fewer Nations*, N.Y. TIMES (Sept. 17, 2008), <http://www.nytimes.com/2008/09/18/us/18legal.html>. The *Roper* decision eliminated the death penalty for juveniles. In the majority opinion, Justice Kennedy cited to a number of international sources, including the United Nations Convention on the Rights of the Child, the African Charter of the Rights and Welfare of the Child, and the UK’s Criminal Justice Act. *Id.* *Lawrence* struck down a Texas statute that prohibited sexual conduct between same-sex individuals. In *Lawrence*, “Justice Kennedy cited three decisions of the European Court of Human Rights, noting that homosexual conduct was accepted as ‘an integral part of human freedom’ in many countries.” *See id.*

154 *Lenahan v. United States*, Case 12.626, Inter-Am. Comm’n H.R., Report No. 80/11, ¶ 42 (2011) (emphasis added).

Gonzales.<sup>155</sup> Gonzales, a woman of Native American and Latin descent who worked as a janitor, had a restraining order against her husband, Simon Gonzales.<sup>156</sup> The restraining order specified dates and times when Simon could visit the children.<sup>157</sup> On the evening of June 22, 1999, Simon took the children on an unscheduled date; despite Ms. Gonzales's multiple police calls to request enforcement of the restraining order, police did not respond.<sup>158</sup> At 3:20 a.m., Simon arrived at the police station and opened fire; police shot back, killing him.<sup>159</sup> The bodies of Ms. Gonzales's three children were found in her husband's pickup truck.<sup>160</sup>

Ms. Gonzales took her case through to the Supreme Court, where the Court held that she did not have a valid claim under Fourteenth Amendment due process.<sup>161</sup> In 2011, Ms. Gonzales, referred to as Jessica Lenahan since her remarriage in the intervening years, took her case to the IACHR.<sup>162</sup> The Commission disagreed with the Supreme Court's holding that Ms. Lenahan was not entitled to judicial remedy, claiming that fundamental human rights in the American Declaration had been violated and that the Supreme Court had failed to properly acknowledge those violations.<sup>163</sup>

The IACHR found for Ms. Lenahan under Articles I, II, VII, and XVIII.<sup>164</sup> In the following analysis, Articles I, II and XVIII will be applied to the U.S. context—demonstrating how the American Declaration can operate to dismantle the system of victimization perpetuated against low-income women of color.

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155 *Castle Rock v. Gonzales*, 545 U.S. 748 (2005).

156 *Human Rights Hero*, U.S. HUM. RTS. FUND (2011), <http://www.racialjustice.org/convening-human-rights-hero.php>; see also *Lenahan*, Case 12.626 ¶ 71.

157 *Castle Rock*, 545 U.S. at 752–53.

158 *Id.* at 753–54.

159 *Id.* at 754.

160 *Id.*

161 See generally *id.*

162 See generally *Lenahan v. United States*, Case 12.626, Inter-Am. Comm'n H.R., Report No. 80/11 (2011).

163 *Id.* ¶ 5.

164 *Id.* The Commission lumped Gonzales's Article XXIV and IV claims under Article XVIII, finding that Article XVIII sufficiently addressed her other two allegations. *Id.* ¶ 200. The IACHR did "not find that it ha[d] sufficient information to find violations of articles V and VI." *Id.*

1. *Article I: Every human being has the right to life, liberty and the security of his person.*

- a. *Article I's "Right to Security" as Protection Against Policing Culture*

Article I inherently implicates law enforcement because the paradigmatic image of an officer is one who protects—one who provides security. But when officers victimize, violate, and perpetuate violence against low-income women of color, the fundamental right to security is lost. Police misconduct works to the detriment of low-income women of color, making them targets for police abuse. As such, this population not only loses an avenue of security vis-à-vis law enforcement, but also comes to fear the very people meant to serve and protect. In police forces across the nation, “lack of institutional will to control [violence] and agency apathy, which [has been] characterize[d] as a dangerously unenlightened ‘boys will be boys’ attitude among police administrators and supervisors,”<sup>165</sup> results in perpetuating a culture of hegemonic masculinity in policing that has largely gone unchecked.

Article I of the American Declaration proclaims security of one's person as a human right. In conceptualizing officers' ability to provide security, it is important to consider security along a spectrum: on one end exists an affirmative duty to protect; on the other end, illustrating a low-threshold of security, exists a duty to refrain from victimizing others. In *Lenahan*, the Commission held that Ms. Lenahan was entitled to protection from police.<sup>166</sup> This assertion affirms that “security,” as used in the Declaration, exists on the end of the spectrum that captures an affirmative duty to protect. No doubt then that security as a human right also encompasses refrain from victimizing others. Police culture as it exists now cannot exist side-by-side with the right to security because the culture of policing seeks to subordinate classes of people—causing widespread victimization, especially among low-income women of color. The right to live free from police victimization results in dismantling the culture of hegemonic

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165 Peter B. Kraska & Victor E. Kappeler, *To Serve and Pursue: Exploring Police Sexual Violence Against Women*, 12 JUST. Q. 85, 89 (1995).

166 *Lenahan*, Case 12.626 ¶¶ 201(6), 213, 215(2).

masculinity in policing.

If security is deemed a basic right in the U.S., then Daniel Holtzclaw and officers like him become outliers rather than the norm. The idea that “boys will be boys” among officers who subordinate and victimize low-income women of color cannot be a common refrain in a society that considers security a right that, at the very least, requires police not to victimize. This is a first step in the erasure of hegemonic masculinity in policing.

b. Article I’s “Right to Life” as Protection Against Increased Police Militarization

Tarika Wilson was a 26-year-old African-American mother.<sup>167</sup>

She died when SWAT officers broke down her front door and opened fire into her home. Ms. Wilson was holding her 14-month-old son when she was shot. The baby was injured, but survived. The SWAT team had been looking for Ms. Wilson’s boyfriend on suspicion of drug dealing when they raided Ms. Wilson’s rented house on the Southside of Lima [Ohio], the only city with a significant African-American population in a region of farmland.<sup>168</sup>

The increased militarization in policing and the use of SWAT teams for drug raids has resulted in loss of security for profiled low-income communities of color. The use of excessive weaponry, including flashbang grenades that “temporarily blind and deafen residents,”<sup>169</sup> in conjunction with the Court-approved use of no-knock warrants,<sup>170</sup> has resulted in an assault on communities of color. These communities are suspended in environments of unpredictability and fear, having no warning of when military-style personnel may enter their homes and debilitate them. According to the ACLU, search warrants may be served simply on “suspicion that someone may be in possession of a small amount of drugs.”<sup>171</sup> Thus, the officers who entered Tarika Wilson’s home needed only suspicion

167 WAR COMES HOME, *supra* note 77, at 5.

168 *Id.*

169 *Id.* at 2.

170 *See* Hudson v. Michigan, 547 U.S. 586 (2006), *supra* section III.B.

171 WAR COMES HOME, *supra* note 77, at 2.



of her boyfriend's drug activity to use fatal force. The officers had no concern for her security or that of her child's, ultimately resulting in Ms. Wilson's death.<sup>172</sup>

Article I declares that there is a fundamental right to life. Increased use of military weapons and SWAT deployments that target low-income communities of color translates into a growing number of unnecessary deaths in these communities at the hands of SWAT teams. The routine use of explosives, military grade firearms, and extreme force presents a disregard for human life. In accepting and adopting the right to life as an underlying right that guides all others, SWAT officers would be required to take added precautions to secure life, reigning in their militant approach and gathering further evidence before breaching individuals' rights under the American Declaration.

2. *Article II: All persons are equal before the law and have the rights and duties established in this Declaration, without distinction as to race, sex, language, creed or any other factor.*

In *Lenahan*, the Commission found that the State did not meet its Article II obligation not to discriminate; the State's lacking responsiveness to domestic violence constituted "a serious human rights violation and an extreme form of discrimination."<sup>173</sup> Additionally, the Commission acknowledged that "certain groups of women face discrimination on the basis of more than one factor during their lifetime, based on their . . . race and ethnic origin, among other [things]."<sup>174</sup> This acknowledgement gives credence to the systemic structures, including law enforcement, which must work to support the dismantling of violence against low-income women of color. However, the U.S., rather than working toward a heightened effort to dismantle the structures of its caste system, has perpetuated, enforced, and maintained this system through Court holdings that have largely sanctioned police misconduct.<sup>175</sup>

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172 See Christopher Maag, *Police Shooting of Mother and Infant Exposes a City's Racial Tension*, N.Y. TIMES (Jan. 30, 2008), <http://www.nytimes.com/2008/01/30/us/30lima.html?mcubz=0>.

173 *Lenahan v. United States*, Case 12.626, Inter-Am. Comm'n H.R., Report No. 80/11, ¶ 162 (2011).

174 *Id.* ¶ 113.

175 See generally *Hudson*, 547 U.S. 586; *Castle Rock v. Gonzales*, 545 U.S. 748 (2005); *Terry v. Ohio*, 392 U.S. 1 (1968).

“The Commission accentuates that this form of mistreatment results in a mistrust that the State structure can really protect . . . from harm, which reproduces social tolerance toward these acts.”<sup>176</sup> Adoption of Article II provides a means to institutionalize a more equitable and non-discriminatory society.

a. Article II as Protection Against Policing Culture that Perpetuates Hegemonic Masculinity

Daniel Holtzclaw systematically targeted low-income women of color based on the premise that this population was societally inferior to others.

Holtzclaw took advantage of both the systemic erasure of black women and the disproportionate power afforded to American police officers to get away with numerous sexual assaults . . . . He deliberately targeted women living on the extreme margins of society—impoverished women, sex workers, drug addicts, all of them black—taking advantage of a system that he knew was rigged in his favour. He knew that these women, from communities that already lived in fear of the police, most likely wouldn’t report him; and, if they did, they almost certainly wouldn’t be believed.<sup>177</sup>

Article II emphasizes equality before the law. If all people are entitled to such equality without regard to race, sex, language, creed, or any other factor, then this provision of the American Declaration serves to hold entities of the law, including law enforcement, to the standard of non-discrimination. Though non-discrimination provisions exist in statutory texts<sup>178</sup> and other components of U.S. law,<sup>179</sup> Article II would serve to bolster

<sup>176</sup> *Lenahan*, Case 12.626 ¶ 167.

<sup>177</sup> Lindy West, *The Case of Serial Rapist Police Officer Daniel Holtzclaw Tells Us So Much About 2015*, THE GUARDIAN (Dec. 13, 2015, 3:00 PM), <https://www.theguardian.com/commentisfree/2015/dec/13/daniel-holtzclaw-rape-convictions-oklahoma-city-police-officer>.

<sup>178</sup> See, e.g., 20 U.S.C. § 1681 (2002); 29 U.S.C. §§ 621–634 (1967); 42 U.S.C. § 2000e(k) (1978); 42 U.S.C. §§ 12101–12213 (1990).

<sup>179</sup> The Declaration of Independence states that “all men are created equal . . .” and the Fourteenth Amendment of the U.S. Constitution provides for “equal protection of the laws.” See THE DECLARATION OF INDEPENDENCE para. 2 (U.S. 1776); U.S. CONST. amend. XIV, § 1.



these already-existing provisions. Furthermore, there is immense strength in accepting and adopting non-discrimination as part of a human rights framework that stresses fundamental, inherent, and inalienable rights for *all* humans. By holding entities of the law to non-discrimination as a human right, the culture of hegemonic masculinity in policing is undermined. In a society that remains true to principles of equality and nondiscrimination, the sentiment of inferiority dissipates.

#### b. Article II as Protection Against Problematic Policing Policies

Officers are guilty of racial profiling, particularly in low-income neighborhoods.<sup>180</sup> Racial profiling tactics throughout the War on Drugs have resulted in increased *Terry* stops and use of militarized forces, causing mayhem for low-income women of color.<sup>181</sup> Racial profiling tactics have trickle-down effects on incarceration rates, which skew towards low-income minorities.<sup>182</sup> Due to concentrated profiling in low-income communities of color, more individuals in these communities are incarcerated;<sup>183</sup> incarceration often results in future difficulty securing employment and difficulty in remaining economically self-sufficient.<sup>184</sup> On the other hand, a manifestation of Article II in policing would have positive trickle-down effects; racial profiling would decrease and as a result, invasive policing against targeted groups, including low-income women of color, would also dwindle. Incarceration rates would more accurately reflect criminal demographics and therefore, incarceration would lack the disproportionate negative effects on low-income women of color. Without systemic racial profiling in policing, low-income women of color are provided with greater opportunity to climb the societal hierarchy through “clean” records that provide greater prospects for stable employment.<sup>185</sup> The positive effects of nondiscrimination in policing not only exist in the present, but also reverberate into the future—providing relief

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180 See *supra* sections III.A.2, III.B–C.

181 Donna Murch, *Crack in Los Angeles: Crisis, Militarization, and Black Response to the Late Twentieth-Century War on Drugs*, 102 J. AM. HIST. 162 (2015).

182 See *supra* sections III.A.2, III.C.

183 *Id.*

184 Amy L. Solomon, *In Search of a Job: Criminal Records as Barriers to Employment*, 270 NAT'L INST. JUST. (2012), <https://www.nij.gov/journals/270/pages/criminal-records.aspx>.

185 *Cf. id.* (detailing the negative repercussions of a criminal record).

for subsequent generations born to low-income women of color.

3. *Article XVIII: Every person may resort to the courts to ensure respect for his legal rights. There should likewise be available to him a simple, brief procedure whereby courts will protect him from acts of authority that, to his prejudice, violate any fundamental constitutional rights. (The right to judicial protection and redress)*

In *Lenahan*, the Article XVIII claim arose partially from insufficient investigation into the children's deaths.<sup>186</sup> The Commission found that the two domestic investigative bodies largely focused on Simon Gonzales's death, but not those of the children.<sup>187</sup> Though the investigative bodies issued conclusive documents on the children's deaths, they "fail[ed] to provide any foundation for [their] premise."<sup>188</sup> Additionally, Ms. Lenahan's repeated requests for investigative reports and data consistently went unheeded.<sup>189</sup> As such, the U.S. violated the fundamental right to judicial protection for absence of a "prompt, thorough, exhaustive and impartial investigation into the deaths of [Ms. Lenahan's children]."<sup>190</sup> The violation also arose from the lack of transparency that surrounded the investigation.<sup>191</sup> The Commission spoke to the right to access information in investigations as a fundamental component in judicial protection and redress.<sup>192</sup> Jessica Lenahan did not receive this transparency of information, leading her to consistently question the cause of her children's death.

The IACHR also spoke to the possible lack of institutional review at the municipal and federal levels.<sup>193</sup> Absence of review results in lost opportunities to gather institutional knowledge

186 *Lenahan v. United States*, Case 12.626, Inter-Am. Comm'n H.R., Report No. 80/11, ¶ 185 (2011).

187 *Id.* ¶ 186.

188 *Id.*

189 *Id.* ¶ 194.

190 *Id.* ¶ 196.

191 *Cf. id.* ¶ 195 (stating that "under the American Declaration, the State is obligated to . . . *communicate the results of . . . an investigation to family.*" (emphasis added)); *see also id.* ¶ 196 (holding that "the United States violated the right to judicial protection . . . at two levels." The State "*failed to convey information to the family members related to the circumstances of the . . . [children's] deaths.*" (emphasis added)).

192 *Id.* ¶ 196.

193 *Id.* ¶ 180.

about appropriate responses for the future that align with the duty to protect.

a. Article XVIII as a Means to Provide Sufficient and Transparent Investigations

The IACHR's acknowledgement that the U.S. violated Ms. Lenahan's right to judicial redress under Article XVIII sheds light on the insufficient nature and lacking transparency in investigations. Such insufficiency operates as a form of police misconduct and discrimination. Low-income women of color are stripped of the justice that emerges through revelation from impartial and complete investigations.

The lack of sufficient investigation and information sharing with victims' loved ones is not a new trend. In October 2013, federal agents shot and killed Miriam Carey, a woman of color who worked as a dental hygienist, because Carey allegedly drove into a White House security checkpoint without authorization.<sup>194</sup> By July 2014, the Justice Department had not released final investigative findings despite requests to make them public.<sup>195</sup> "Capitol Police also stonewalled attempts to gather further information . . . [and] the officers involved in the fatal shooting [were placed] back on duty."<sup>196</sup> In 2014, the D.C. U.S. Attorney's Office announced that there was not enough evidence for criminal or local charges against the officers involved in Carey's death.<sup>197</sup> Carey's family met immense difficulty in seeking redress through legal action, partially due to their inability to access information pertaining to the investigation.<sup>198</sup> Carey's case demonstrates the need to

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194 Hannah Hess, *Miriam Carey Shooting Provokes Lawsuit Against DOJ*, ROLL CALL (Apr. 17, 2015, 1:48 PM), <https://www.rollcall.com/news/miriam-carey-shooting-provokes-lawsuit-against-doj>.

195 *Id.*

196 *Id.*

197 Tom Roussey et al., *Officers Who Shot and Killed Miriam Carey Near U.S. Capitol in October Found Not at Fault*, WJLA (July 10, 2014), <http://wjla.com/news/local/officers-who-shot-and-killed-miriam-carey-near-u-s-capitol-in-october-found-not-at-fault-104964>.

198 See generally Hannah Hess, *One Year Later, Family Protests Miriam Carey Shooting on Capitol Hill*, ROLL CALL (Oct. 3, 2014, 11:20 AM), <http://www.rollcall.com/hill-blotter/one-year-later-family-protests-miriam-carey-shooting-on-capitol-hill/?dcz> (stating that the Carey family asked Congress to investigate, but lawmakers trusted the DOJ report that exonerated the officers; at the time of the article's publication in 2014, the Capitol Police Department was still conducting an internal review of the shooting); see also Hess, *Miriam*

improve upon both the transparency and depth of investigations, particularly for low-income women of color.

**b. Article XVIII as a Means to Rectify Systemic Failures in the Duty to Protect**

In *Lenahan*, the Commission also spoke to systemic failures in the U.S. that breached the affirmative duty to provide protection.<sup>199</sup> The IACHR held that the U.S. should undertake an inquiry to understand its systemic failures.<sup>200</sup> However, the Commission stated that it did not have information regarding whether such an inquiry had been conducted at the municipal or federal levels.<sup>201</sup> At the municipal level, the Castle Rock police did not respond to Ms. Lenahan’s repeated requests to retrieve her children after they were taken by Simon,<sup>202</sup> constituting police misconduct through inaction. At the federal level, Ms. Lenahan’s husband, subject to a restraining order and having a criminal history,<sup>203</sup> was able to receive FBI approval for a gun purchase.<sup>204</sup>

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*Carey Shooting Provokes Lawsuit Against DOJ*, *supra* note 194 (stating that police stonewalled attempts to gather information and that the suit was still pending (as of 2015 when the article was published)).

199 *Lenahan v. United States*, Case 12.626, Inter-Am. Comm’n H.R., Report No. 80/11, ¶ 180 (2011).

200 *Id.* ¶ 179.

201 *Id.* ¶ 180.

202 *Castle Rock v. Gonzales*, 545 U.S. 748, 753–54 (2005).

203 “Throughout Jessica Lenahan’s relationship with Simon Gonzales he demonstrated ‘erratic and emotionally’ abusive behavior towards her and her daughters.” *Lenahan*, Case 12.626 ¶ 65. When Ms. Lenahan initially requested a restraining order, she wrote that Simon was violent and posed an imminent danger of harm, citing his attempt to hang himself in the garage in the presence of his daughters. *Id.* ¶ 66. “Simon Gonzales’s criminal history shows that he had several run-ins with the police in the three months preceding June 22, 1999. Jessica Lenahan called the Castle Rock Police Department on at least four occasions during those months to report domestic violence incidents. She reported that Simon Gonzales was stalking her, that he had broken into her house and stolen her wedding rings, that he had entered into her house unlawfully to change the locks on the doors, and that he had loosened the water valves on the sprinklers outside her house so that water flooded her yard and the surrounding neighborhood. Simon Gonzales also received a citation for road rage on April 18, 1999, while his daughters were in his car without seatbelts, and his drivers’ license had been suspended by June 23, 1999.” *Id.* ¶ 67. Furthermore, Simon was charged with trespass and with the obstruction of public officials, and a non-extraditable warrant for Simon’s arrest had been issued in Larimer County by June 23, 1999. *Id.* ¶¶ 68, 69.

204 *Id.* ¶ 159. In accordance with 18 U.S.C. § 922(d)(8) (2012): “It shall be

Given the possible absence of review to rectify the municipal and federal inadequacies, Ms. Lenahan never learned how the systems that failed her were rectified. Such lacking review translates into maintaining inadequate responses that result in systemic failures. These systemic failures perpetuate violence against low-income women of color by neglecting to rectify patterns of misconduct that adversely impact this population.

Six months after Miriam Carey's shooting, Congressional members in committees having jurisdiction over Capitol Police and law enforcement showed little interest in investigating her death.<sup>205</sup> Attorney Eric Sanders responded by saying that "it is in the public's interest to ensure our government acted responsibly . . . . It is also in the public's interest [to] avoid a similar tragedy in the future."<sup>206</sup> Sanders's quote speaks to investigations as a necessity. Investigations serve as a broader inquiry that provide suggestions for internal improvement. More importantly, such inquiry sheds light on systemic failures that cripple the duty to protect. By investigating allegations of police misconduct, States can determine their failings and appropriately respond to these shortcomings in order to aptly fulfill their affirmative duty to protect.

The fact that low-income women of color do not have judicial protection and redress, a fundamental right described in Article XVIII of the American Declaration, means that they are consistently disadvantaged. Low-income women of color and their families are denied the right to depth and transparency in investigations and are placed at risk due to reluctance to inquire into systemic failures that abridge the duty to protect. In *Lenahan*,

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unlawful for any person to sell or otherwise dispose of any firearm or ammunition to any person knowing or having reasonable cause to believe that such person is subject to a court order that restrains such person from harassing, stalking, or threatening an intimate partner of such person or child of such intimate partner or person, or engaging in other conduct that would place an intimate partner in reasonable fear of bodily injury to the partner or child . . . ." This statutory provision is written in Colorado's permanent order. See COLO. JUDICIAL DEPT., FORM NO. JDF 399 R9/13, PERMANENT CIVIL PROTECTION ORDER 4 (2013), [https://www.courts.state.co.us/Forms/PDF/JDF%20399T%20Permanent%20Protection%20Order%20Rev%2009%2013%20\(FINAL\).pdf](https://www.courts.state.co.us/Forms/PDF/JDF%20399T%20Permanent%20Protection%20Order%20Rev%2009%2013%20(FINAL).pdf). As such, Simon Gonzales should not have passed the seller's processed FBI background check.

205 Hannah Hess, *Congress Takes Hands-Off Approach to Miriam Carey Shooting*, ROLL CALL (Apr. 14, 2014, 12:50 PM), <http://www.rollcall.com/hill-blotter/congress-has-no-interest-in-investigating-miriam-carey-shooting/?dcz=>.

206 *Id.*

the lacking responsiveness to domestic violence is illuminating: it demonstrates the State's multitude of failures to respond to problems that heavily impact low-income women of color, including police inaction—a form of police misconduct.

4. *The American Declaration as a Tool for Systemic Change: Holding Municipalities and states<sup>207</sup> Accountable*

Municipalities may be shielded from liability through the doctrine of immunity.<sup>208</sup> In *Lenahan*, Ms. Lenahan's "potential state remedies [including] . . . a civil tort suit under Colorado law against the Town of Castle Rock . . . would have had no possibility of success due to the doctrine of . . . immunity."<sup>209</sup> Individual states are also shielded from liability because they act as sovereign entities that cannot be sued without their consent.<sup>210</sup> The existence of immunity makes it difficult to instill a systemic structure of accountability for police misconduct. The Commission in *Lenahan* stressed that the due diligence requirement of protection extends to all branches of government, thereby allocating responsibility to municipalities and states.<sup>211</sup> Under the American Declaration, immunity would not serve as an affirmative defense for actions perpetrated against low-income women of color.<sup>212</sup> By circumventing the defense of immunity, and by extending due diligence to all levels of government, accountability becomes omniscient—pervading a society that must reckon with its legacy of discrimination and victimization.

## V. Conclusion

Accepting the American Declaration as binding law and ultimately adopting the Declaration as domestic law will operate to dismantle the U.S. caste system that places low-income women of color on the lowest tiers of the social hierarchy. U.S. policing and law have not proven sufficient for breaking the deeply-entrenched

207 Note that state differs from State, in that the former refers to the fifty states of the U.S., whereas the latter refers to the entire nation.

208 Generally, governmental immunity protects government entities from lawsuits, unless the entity has waived immunity. BLACK'S LAW DICTIONARY 2192 (Bryan A. Garner ed., 8th ed. 2004).

209 *Lenahan*, Case 12.626 ¶ 41.

210 BLACK'S LAW DICTIONARY, *supra* note 208.

211 *Lenahan*, Case 12.626 ¶¶ 125, 128.

212 See generally *Lenahan*, Case 12.626.

prejudice against low-income women of color, and rather, have worked to maintain control over this population—severely disadvantaging it. The U.S. needs a human rights framework to combat police brutality and serve as a check on its historical legacy of discrimination and victimization; the American Declaration will serve as such.

## Universities as Disability Rights Change Agents

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## I. Introduction

Historically and globally, children and youth with disabilities have been excluded from primary school education or provided with substandard education relative to their non-disabled peers,<sup>1</sup> despite promulgation of a variety of human rights instruments.<sup>2</sup> Being systemic, such discrimination persists beyond primary school education and raises numerous entrenched barriers to students with disabilities seeking to pursue higher education at the university, graduate, or post-graduate level.<sup>3</sup>

The social and economic implications of this human rights violation are clear: rendering students with disabilities invisible after mandatory primary school education signals that their inclusion can only be tolerated during childhood, if at all, and that no value emanates from their continued learning.<sup>4</sup> Precluding the advanced education of students with disabilities exponentially increases their likelihood for unemployment and poverty, and has enormous secondary effects on physical and mental well-being, social inclusion, and agency as citizens.<sup>5</sup>

This article, part of a symposium honoring the memory and contributions of Professor Hope Lewis, investigates the obligations, practices, and dramatic potential of universities to empower persons with disabilities. Our focus, much in the spirit of Professor Lewis's academic agenda,<sup>6</sup> is on international law and norms,<sup>7</sup>

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1 See Paul Harpur & Michael Ashley Stein, *Children with Disabilities, Human Rights, and Sustainable Development*, in CHILDREN'S RIGHTS AND SUSTAINABLE DEVELOPMENT: IMPLEMENTING THE UNCRC FOR FUTURE GENERATIONS (Claire Fenton-Glynn ed., forthcoming 2018).

2 See *infra* Section II.A.

3 See, e.g., Janette Ryan, *Access and Participation in Higher Education of Students with Disabilities: Access to What?*, 38 AUSTL. EDUC. RESEARCHER 73 (2011).

4 For the expressive effects of inclusive education, see Sarah Arduin, *The Expressive Dimension of Article 24 of the UN Convention on the Rights of Persons with Disabilities*, in THE RIGHT TO INCLUSIVE EDUCATION IN INTERNATIONAL HUMAN RIGHTS LAW (Gauthier de Beco et al. eds., forthcoming 2018).

5 See JODY HEYMANN ET AL., *Disability, Employment, and Inclusion Worldwide*, in DISABILITY AND EQUITY AT WORK 1, 1–5 (Jody Heymann et al. eds., 2014) [hereinafter DISABILITY AND EQUITY]; Frank R. Rusch et al., *Transition from School to Work: New Directions for Policy and Practice*, in DISABILITY AND EQUITY 197, 204–05.

6 Professor Lewis was passionate about realizing human rights and deeply committed to the rights of her fellow persons with disabilities. See *Faculty Directory: Hope Lewis*, NE. U. SCH. OF L., <https://www.northeastern.edu/law/faculty/directory/lewis.html> (last visited Dec. 29, 2017).

7 See, e.g., JEANNE M. WOODS & HOPE LEWIS, HUMAN RIGHTS AND THE GLOBAL MARKETPLACE: ECONOMIC, CULTURAL, AND SOCIAL

although at times we reference United States disability law for its wealth of education-related jurisprudence.<sup>8</sup> Also in the spirit of Professor Lewis's scholarship, we interweave salient narratives by stakeholders—here, students with disabilities in higher education—to ensure that their voices are heard and their concerns are acknowledged.<sup>9</sup>

Section II sets forth a brief overview of how international human rights law, primarily due to the United Nations Convention on the Rights of Persons with Disabilities (CRPD),<sup>10</sup> has evolved so that States Parties are now required to ensure lifelong educational equality for persons with disabilities. Next, Section III enumerates the duties incumbent on universities to comply with the CRPD's mandates, as well as additional commitments that universities can undertake to embrace a role as change agents for disability human rights. Part IV provides a case study of Australian universities with practical examples of how those institutions of higher learning honor, at times fall short, and at times exceed their CRPD obligations. We conclude with some reflections on the propriety of the role of universities to help transform power imbalances for persons with disabilities in their societies.

## II. Universities and Inclusive Education

The right to equally access higher education by persons with disabilities was inferred by the United Nations Convention on the Rights of the Child (CRC),<sup>11</sup> facilitated subsequently by soft law developments, and then instantiated via the CRPD's mandate on equal access to lifelong learning.<sup>12</sup>

### A. The CRC

The CRC went into operation in 1990 and is the first United Nations human rights treaty to expressly enshrine the rights of persons

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DIMENSIONS (2005); Hope Lewis, *Transnational Dimensions of Racial Identity: Reflections on Race, the Global Economy, and the Human Rights Movement at 60*, 24 MD. J. INT'L L. 296 (2009).

8 See, e.g., DEREK W. BLACK, *EDUCATION LAW: EQUALITY, FAIRNESS, AND REFORM* (2013).

9 See, e.g., Hope Lewis, *Lionheart Gals Facing the Dragon: The Human Rights of Inter/National Black Women in the United States*, 76 OR. L. REV. 567 (1997).

10 Convention on the Rights of Persons with Disabilities, *opened for signature* Mar. 30, 2007, 2515 U.N.T.S 3 [hereinafter CRPD].

11 Convention on the Rights of the Child, New York, Nov. 20, 1989, 1577 U.N.T.S 3 [hereinafter CRC] (entered into force Sept. 2, 1990).

12 CRPD, *supra* note 10, at art. 24.

with disabilities.<sup>13</sup> Article 23(3) requires States Parties “to ensure” that children with disabilities within their jurisdiction have access to “education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities.”<sup>14</sup> In doing so, the CRC requires significant efforts from States to prepare children with disabilities for life and future education. At the same time, the CRC enshrines the rights of persons with disabilities only until they reach the age of majority or turn 18 years old and cease to be classified as children,<sup>15</sup> and does not require that post-primary school education be non-discriminatory or accessible.<sup>16</sup>

### B. Soft Laws

Soft laws adopted following the CRC expanded the focus from children with disabilities to all persons with disabilities regardless of age; specifically, the 1993 Standard Rules on the Equalization of Opportunities for Persons with Disabilities (Standard Rules),<sup>17</sup> and the 1994 Salamanca Statement and Framework for Action on Special Needs Education (Salamanca Statement)<sup>18</sup> each apply to children, youth, and adults with disabilities. Rule 6 of the Standard Rules requires States to recognize the principle of equal educational opportunities in primary, secondary, and tertiary education for persons with disabilities of all ages.<sup>19</sup> Rule 6(5) provides for a range of special measures, including for adult women with disabilities.<sup>20</sup>

Following adoption of the Standard Rules, representatives of 92 governments and 25 international organizations formed the World Conference on Special Needs Education in 1994 and adopted the Salamanca Statement, which introduced a paradigm shift from

13 Vanessa Torres Hernandez, *Making Good on the Promise of International Law: The Convention on the Rights of Persons with Disabilities and Inclusive Education in China and India*, 17 PAC. RIM L. & POL'Y J. 497 (2008); see also CRC, *supra* note 11.

14 CRC, *supra* note 11, at art. 23(3).

15 *Id.* at art. 1.

16 Harpur & Stein, *supra* note 1.

17 G.A. Res. 48/96, Standard Rules on the Equalization of Opportunities for Persons with Disabilities, 202 U.N. Doc. A/48/49 (Dec. 20, 1993) [hereinafter Standard Rules]. The Standard Rules enumerate 22 guidelines that summarize and make operational the outcomes of the 1982 *World Programme of Action Concerning Disabled Persons*. G.A. Res. 37/52, World Programme of Action Concerning Disabled Persons, U.N. Doc. A/37/51 (Dec. 3, 1982).

18 UNESCO, THE SALAMANCA STATEMENT AND FRAMEWORK FOR ACTION ON SPECIAL NEEDS EDUCATION (1994) [hereinafter SALAMANCA STATEMENT].

19 Standard Rules, *supra* note 17, at r. 6.

20 *Id.* at r. 6(5)(c).

integrated to inclusive education for persons with disabilities.<sup>21</sup> Paragraph 16 recognizes the right of adults with disabilities to tertiary education,<sup>22</sup> paragraph 57 references the need to target adult learning to different needs,<sup>23</sup> and paragraphs 16 and 17 explain that States should enshrine these rights in legislation and adopt measures to effectuate them.<sup>24</sup>

### C. The CRPD

In 2006, the CRPD established the human rights of persons with disabilities as full and equal citizens.<sup>25</sup> Building on the groundwork laid by the above referenced soft law instruments,<sup>26</sup> Article 24 extends the CRC's right to education from primary education to "an inclusive education system at all levels and lifelong learning," thereby encompassing university and graduate education.<sup>27</sup> This right to lifelong education represents a substantial change in how persons with disabilities have enjoyed rights protection in this space.<sup>28</sup> Notably, the right to education is among the more strongly worded of the CRPD articles, with each of its five sub-articles utilizing directive phrases such as "shall"<sup>29</sup> and "ensure."<sup>30</sup>

The Committee on the Rights of Persons with Disabilities (CRPD Committee)—which is tasked with interpreting, monitoring, and enforcing the terms of the treaty<sup>31</sup>—issued *General Comment*

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21 Florian Kiuppis, *Why (not) Associate the Principle of Inclusion with Disability? Tracing Connections from the Start of the Salamanca Process*, 18 INT'L J. INCLUSIVE EDUC. 746, 747 (2014).

22 SALAMANCA STATEMENT, *supra* note 18, ¶ 16.

23 *Id.* ¶ 57.

24 *Id.* ¶¶ 16–17.

25 Michael Ashley Stein, *Disability Human Rights*, 95 CALIF. 75 (2007), *reprinted in* NUSSBAUM AND LAW 3 (Robin West ed., 2015); *reprinted in* VULNERABLE AND MARGINALIZED GROUPS AND HUMAN RIGHTS 665 (David Weissbrodt & Mary Rumsey eds., 2011).

26 See Michael Ashley Stein & Janet E. Lord, *Future Prospects for the United Nations Convention on the Rights of Persons with Disabilities*, in THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES: EUROPEAN AND SCANDINAVIAN PERSPECTIVES 17 (Gerard Quinn & Oddný Mjöll Arnardóttir eds., 2009).

27 CRPD, *supra* note 10, at art. 24.

28 Payel Rai Chowdhury, *The Right to Inclusive Education of Persons with Disabilities: The Policy and Practice Implications*, 12 ASIA-PACIFIC J. ON HUM. RTS. & L. 1, 15 (2011).

29 CRPD, *supra* note 10, at art. 24 (1)–(5).

30 *Id.* at art. 24(2).

31 See Janet E. Lord & Michael Ashley Stein, *The Committee on the Rights of Persons with Disabilities*, in THE UNITED NATIONS AND HUMAN RIGHTS: A

No. 4 in 2016 to explain the normative content and prescriptive requirements of Article 24.<sup>32</sup> The General Comment, entitled “Right to Inclusive Education,” requires that sufficient places exist where persons with disabilities can be educated,<sup>33</sup> and that education be affordable.<sup>34</sup> It likewise stresses that, to achieve equality, educational systems need to be accessible at all levels, including through the built environment, instructional materials, information and communication technologies, teaching techniques, and assessments.<sup>35</sup>

By expanding the right to education from basic primary schooling to lifelong learning, the CRPD enables students with disabilities to demand inclusive university and graduate school education under international human rights law for the first time.<sup>36</sup>

### III. Universities as Disability Rights Change Agents

As of this writing, 175 of the 193 United Nations Member States have ratified the CRPD,<sup>37</sup> giving the treaty’s mandates—including that of inclusive higher education—overwhelming moral and formal legal gravitas.<sup>38</sup> In addition, because the vast majority of universities globally are State-based, operate pursuant to State sanction, or receive State funding,<sup>39</sup> they are legally bound to enable

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CRITICAL APPRAISAL (Philip Alston & Frédéric Mégret eds., forthcoming 2018).

32 Comm. on the Rights of Persons with Disabilities, General Comment No. 4 (2016) on the Right to Inclusive Education, ¶¶ 8–19, U.N. Doc CRPD/C/GC/4 (Nov. 25, 2016) [hereinafter General Comment No. 4].

33 *Id.* ¶ 20.

34 *Id.* ¶ 23.

35 *Id.* ¶ 21.

36 Harpur & Stein, *supra* note 1.

37 See *Chapter IV: Human Rights*, UNITED NATIONS TREATY COLLECTION, [https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtmsg\\_no=IV-15&chapter=4&clang=\\_en](https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtmsg_no=IV-15&chapter=4&clang=_en) (last updated Mar. 3, 2018) (providing an up-to-date list of signatures and ratifications to the CRPD).

38 Reflecting the overwhelming global ratification of the CRPD, customary international law engenders obligations States—and their subsidiary parts, such as universities—that have yet to formerly ratify the treaty. The implications of this point are illustrated in the context of education in pre-ratification Canada by Ravi Malhotra & Robin F. Hansen, *The United Nations Convention on the Rights of Persons with Disabilities and its Implications for the Equality Rights of Canadians with Disabilities: The Case of Education*, 29 WINDSOR Y.B. ACCESS JUST. 73, 74 (2011).

39 For example, there are three private and 37 public universities in Australia. See *Data Snapshot 2017*, UNIVERSITIES AUSTRALIA (Mar. 27, 2017), <https://www.universitiesaustralia.edu.au/australias-universities/key-facts-and->



the disability human rights paradigm set out in the CRPD's articles.<sup>40</sup> Accordingly, universities incur equality duties which are then operationalized through disability support offices, admission offices, deans, professors, library staff, campus police, human resources, and a range of other groups operating within the arcane and complex bureaucratic structure of higher education systems.<sup>41</sup> Individuals and departments within these large organizational structures, even when seemingly acting with good intentions,<sup>42</sup> at times overlook disability as a sector,<sup>43</sup> have competing agendas,<sup>44</sup> communicate poorly amongst themselves,<sup>45</sup> or lack the skills to interact with persons with disabilities.<sup>46</sup>

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- 40 Parenthetically, we note that increasingly, non-State actors—which here could include private universities—are being viewed as human rights duty bearers. See generally ANDREW CLAPHAM, *HUMAN RIGHTS OBLIGATIONS OF NON-STATE ACTORS* (Oxford ed., 2006); NON-STATE ACTORS AND HUMAN RIGHTS (Philip Alston ed., 2005).
- 41 Cf. Frank Eyetsemitan, *Understanding Institutional Climate*, in *THE RESOURCE HANDBOOK FOR ACADEMIC DEANS* 57 (Laura L. Behling ed., 3d ed. 2014).
- 42 To cite a prominent and regretful oversight, a Harvard College taskforce mentions disability in the context of legal compliance and reporting obligations but otherwise largely neglects this student population in discussions of educational and social “inclusion.” See COLL. WORKING GRP. ON DIVERSITY AND INCLUSION, *REPORT OF THE COLLEGE WORKING GROUP ON DIVERSITY AND INCLUSION* (2015), [http://diversity.college.harvard.edu/files/collegediversity/files/diversity\\_and\\_inclusion\\_working\\_group\\_final\\_report\\_2.pdf?m=1447857004](http://diversity.college.harvard.edu/files/collegediversity/files/diversity_and_inclusion_working_group_final_report_2.pdf?m=1447857004).
- 43 Elizabeth Lepro, *Diversity includes Disability*, *THE PITT NEWS* (Apr. 25, 2016), <https://pittnews.com/article/107584/featured/diversity-includes-disability/>; The Michigan Daily Editorial Board, *Don't Ignore Disability*, *THE MICHIGAN DAILY* (Feb. 7, 2017, 5:53 PM), <https://www.michigandaily.com/section/editorials/daily-make-u-more-accessible>.
- 44 For example, in 2016, Student Disability Services at the University of Iowa decided it was unable to keep up with accommodation requests by students with disabilities and stopped providing examination-taking accommodations. The administration of these tests now rests with Iowa's various faculties and colleges, who in turn complain that they are inadequately resourced to do so. See Katelyn Weisbrod, *UI Axes Special Testing for Students with Disabilities*, *THE DAILY IOWAN* (Mar. 24, 2016), <http://daily-iowan.com/2016/03/24/ui-axes-special-testing-for-students-with-disabilities/>.
- 45 See Bookyung Jo, *Student Disabilities Services Receives Mixed Reviews*, *THE DAILY PENNSYLVANIAN* (Feb. 25, 2015, 1:28 AM), <http://www.thedp.com/article/2015/02/student-disabilities-service> (reporting the days-long stranding of a wheelchair-using college student in his accommodation due to ice not being cleared from footpaths).
- 46 Abby Mitchell, *Disability Access Severely Lacking on Campus*, *COLUMBIA SPECTATOR* (Nov. 26, 2016, 4:00 PM), <http://www.columbiaspectator>.

In the context of higher education, CRPD Article 24(5) requires States Parties to provide persons with disabilities access to tertiary education without discrimination and on an equal basis with others.<sup>47</sup> To comply with this mandate and thereby act as change agents for disability rights, universities must ensure: equality in admissions; universal design, universal design for learning, and reasonable accommodations; access to information and communication technologies; support in extracurricular activities; the hiring of academic and other staff with disabilities; and the facilitation of the transition of students with disabilities to the workplace.<sup>48</sup> Each of these is discussed in turn.

### A. Admissions

Exclusion based upon merit is not a prohibited form of disability discrimination under the CRPD, in contrast to rejection arising from disability status.<sup>49</sup> Hence, it would be discriminatory for a university to bar deaf applicants on the basis of their being deaf. Conversely, it would be permissible for that same university to qualify admission based upon neutral and evenly applied entry criteria, for example, requiring that all applicants be able to comprehend the national language spoken in all classes.<sup>50</sup>

Problems arise, however, where the drafting or application of standards are performed in a discriminatory manner (e.g., an “oral” test that precludes answers being given in sign language) or where criteria have a disparate impact upon applicants with disabilities (such as a hearing test as an unrelated qualification for admission).<sup>51</sup>

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com/opinion/2014/04/17/disability-access-severely-lacking-campus/ (citing the example of public safety officers who were not informed on disability protocols).

47 CRPD, *supra* note 10, at art. 24(5).

48 See generally General Comment No. 4, *supra* note 32, ¶¶ 12(g), 21, 34.

49 *Id.* ¶ 18.

50 See Wanda Hadley & D. Eric Archer, *College Students with Learning Disabilities: An At-Risk Population Absent from the Conversation of Diversity*, in *DISABILITY AS DIVERSITY IN HIGHER EDUCATION: POLICIES AND PRACTICES TO ENHANCE STUDENT SUCCESS* 75 (Eunyoung Kim & Katherine C. Aquino eds., 2017) [hereinafter *DISABILITY AS DIVERSITY*] (analyzing how college students with learning disabilities can be omitted in the disability inclusion debate); Kevin Walker, *Comparing American Disability Laws to the Convention on the Rights of Persons with Disabilities with Respect to Postsecondary Education for Persons with Intellectual Disabilities*, 12 *NW. J. INT'L. HUM. RTS.* 115, 118 (2014) (“[D]isabled persons cannot be discriminated against and denied admission to a postsecondary educational institution on the basis of their disability.”).

51 See, e.g., Michael Schwartz, *Technical Standards for Admission to Medical School: Deaf Candidates Don't Get No Respect*, 28 *BUFF. PUB. INT. L.J.* 31, 47 (2009)



Consequently, the line between lawful and unlawful requirements is frequently contested and can be uncertain.<sup>52</sup> Moreover, evidence indicates that hostility remains in accepting students with disabilities into various professional programs.<sup>53</sup>

Universities should develop clear essential requirement statements for each program that are appropriately available to prospective students. In developing these guidelines, faculty should consult with experts across the university and more broadly, as required. This process will help identify inappropriate restrictions, and enable such erroneous criteria to be challenged, discussed, and hopefully resolved before discrimination occurs. Further, public disclosure of these requirements will enable prospective students with disabilities to make better informed choices about which university and courses they should consider enrolling in.<sup>54</sup> To illustrate: despite its impressive academic reputation, a sociology major with physical disabilities at Columbia University reported that he was unable to enter the wheelchair inaccessible sociology department.<sup>55</sup> Nearly a decade since his graduation, the status quo of building accessibility remains relatively unchanged.<sup>56</sup>

Nor is a hostile environment unique to Columbia. The Yale Daily News reported that in 2017, a single undergraduate on

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(noting that educators cannot “use eligibility standards or criteria that screen out or tend to screen out qualified applicants with disabilities simply because they are disabled.”).

52 See, e.g., *Se. Cmty. Coll. v. Davis*, 442 U.S. 397, 405, 414 (1979) (holding that a nursing school could exclude a deaf student for lack of “reasonable physical qualifications” meaning hearing). This case has not been formerly overruled, yet most education law experts would construe it as being in contravention of the Rehabilitation Act and the Americans with Disabilities Act.

53 Michael McKee et al., *Medical Schools’ Willingness to Accommodate Medical Students with Sensory and Physical Disabilities: Ethical Foundations of a Functional Challenge to “Organic” Technical Standards*, 18 *AMA J. ETHICS* 992, 993 (2016).

54 In this respect, we stress the function of transparency as an aid to assessing the culture of these institutions and the attendant supports they provide in order to make educated decisions, including whether and how to challenge discriminatory barriers, and unequivocally not as barriers or disincentives to application. Parallel arguments have been made for the employment context. See Lisa Schur et al., *Corporate Culture and the Employment of Persons with Disabilities*, 23 *BEHAV. SCI. & L.* 3, 11 (2005) (analysing the positive and negative impact of corporate culture on the working experiences of persons with disabilities).

55 Abby Mitchell, *Disability Access Severely Lacking on Campus*, *COLUMBIA SPECTATOR* (Nov. 26, 2016, 4:00 PM), <http://www.columbiaspectator.com/opinion/2014/04/17/disability-access-severely-lacking-campus/>.

56 *Id.*

campus used a wheelchair.<sup>57</sup> Worse was that almost 14% of Yale students strongly disagreed or disagreed with the statement that “Yale would benefit by having more students with disabilities on campus.”<sup>58</sup> At Stanford, a graduate student reported that when he commenced study, there were no academics named as disability scholars.<sup>59</sup> A Harvard University freshman explained that students with disabilities do not have a collective voice, and systems fail to understand that disability can be experienced in so many ways.<sup>60</sup> This student observed that persons with disabilities “are the largest minority with the least representation” at Harvard University.<sup>61</sup>

Although informing students of discriminatory practices is empowering, the process of self-selection can result in persons with disabilities having no exposure in certain courses or universities, thus reinforcing erroneous and discriminatory beliefs of staff and students.<sup>62</sup> Informing potential students that a course or university does not uphold disability human rights is important, but it is a small step in reversing the underlying barriers to equality.

### ***B. Universal Design, Universal Design for Learning, and Reasonable Accommodations***

Article 24 requires States Parties to “ensure an inclusive education system at all levels.”<sup>63</sup> Following on *General Comment No. 4*, inclusive education is possible only where universities promote disability inclusive design and universal design for learning, while also ensuring the provision of reasonable accommodations when these fall short.<sup>64</sup>

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57 Anastasiia Posnova, *An Invisible Minority*, YALE DAILY NEWS (Nov. 3, 2017), <https://yaledailynews.com/blog/2017/11/03/an-invisible-minority/>.

58 *Id.*

59 Olivia Mitchel, *Classy Classes: Human Rights Class Explores Disabilities Studies*, THE STANFORD DAILY (Nov. 15, 2017), <https://www.stanforddaily.com/2017/11/15/classy-classes-human-rights-class-explores-disabilities-studies/>.

60 See Devon Black, *Living with a Terminal Illness at Harvard*, THE TAB (Feb. 1, 2016), <https://thetab.com/us/harvard/2016/02/01/living-cystic-fibrosis-harvard-2094>.

61 *Id.*

62 See Deann Lechtenberger et al., *Using Wraparound to Support Students with Developmental Disabilities in Higher Education*, 46 C. STUDENT J. 856 (2012).

63 CRPD, *supra* note 10, at art. 24(1).

64 Jacqueline Shoonheim & David Ruebain, *Reflections on Inclusion and Accommodation in Childhood Education: From International Standard Setting to National Implementation*, in DISABILITY RIGHTS IN EUROPE: FROM THEORY TO PRACTICE 163 (Anna Lawson & Caroline Gooding eds., 2005).

CRPD Article 2 defines universal design as “the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.”<sup>65</sup> When conceptualizing products or systems, the designer identifies who needs to be able to use the product, which, by implication, involves a determination of a “normal” user.<sup>66</sup> The process of creating the “norm” can involve subtle and overt forms of ableism. To avoid discrimination for products and systems in the education sector, the concept of the “normal” student should be constructed to include students with and without disabilities, and incorporate their respective needs.<sup>67</sup> This means that students with and without disabilities should be able to sleep in college dorms, eat, travel, study, enter buildings, access digital content, and take advantage of all opportunities associated with their university experience “without the need for adaptation or specialized design.”<sup>68</sup>

The CRPD Committee specifically addressed inclusive education as part of its *General Comment No. 2* on accessibility.<sup>69</sup> *General Comment No. 2* provides: “[I]t is the entire process of inclusive education that must be accessible, not just buildings, but all information and communication, including ambient or FM assistive systems, support services and reasonable accommodation in schools.”<sup>70</sup> The CRPD thus requires States Parties, and their constituent parts, such as state universities, to guarantee equality in the “entire process” of education; whether it be in the physical or digital environments, in teaching techniques, or any other aspect of

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65 CRPD, *supra* note 10, at art. 2.

66 See generally ROB IMRIE & PETER HALL, *INCLUSIVE DESIGN: DESIGNING AND DEVELOPING ACCESSIBLE ENVIRONMENTS* (2001) (analyzing how regulatory controls are increasingly requiring development teams to design the built environment in ways which are sensitized to the needs of people with a range of disabilities).

67 Valentina Della Fina, *Article 24 [Education]*, in *THE UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES* 447–51 (Valentina Della Fina et al. eds., 2017) (arguing that Article 24 of the CRPD recognizes the right to inclusive education as a means to make the universal right to education effective for people with disabilities).

68 Jason Scott Palmer, *The Convention on the Rights of Persons with Disabilities: Will Ratification Lead to a Holistic Approach to Postsecondary Education for Persons with Disabilities*, 43 *SETON HALL L. REV.* 551, 583 (2013).

69 Comm. on the Rights of Persons with Disabilities, *General Comment No. 2* (2014), Article 9: Accessibility, U.N. Doc. CRPD/C/GC/2 (May 22, 2014) [hereinafter *General Comment No. 2*].

70 *Id.* ¶ 39.

students' educational experience.<sup>71</sup>

Relatedly, universities should adopt universal design for learning so that all students, including those with disabilities, have their respective individual learning needs met. Importantly, universal design is not simply about disability inclusion; it is about enhancing the educational experience for all students. Professor Thomas Hehir observes that universal design in the education sector promotes teaching strategies, materials, and technologies that will benefit a wide variety of individuals, not just those with disabilities.<sup>72</sup> In the physical space, disability inclusive buildings can enable people who lack fitness, have a temporary incapacity, or are carrying a heavy bag full of textbooks to use the building. Sub-titles on videos can assist deaf students to learn, but can also enable students with no impairments to view content in noisy environments, such as on the bus, and can help international students with limited English absorb content. Universal design in education is not just about disability inclusion, it is about promoting human diversity and access for all.

Yet, despite the prevalence of information on universal design and universal design for learning<sup>73</sup>—as well as their education, social justice, and cost efficiency implications<sup>74</sup>—universities commonly do not implement these universal principles.<sup>75</sup> As a consequence of this neglect, universities are required by CRPD Article 24(1) to provide reasonable accommodations to ensure equal access for

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71 *Id.*

72 THOMAS HEHIR, *NEW DIRECTIONS IN SPECIAL EDUCATION* 86–110 (2005).

73 One well recognised standard, and one that the CRPD Committee encourages States Parties to apply, is the Universal Design for Learning (UDL) approach. General Comment No. 4, *supra* note 32, ¶ 26. Despite the information on inclusive design, more work is needed to design means of implementing the CRPD. Payel Rai Chowdhury, *The Right to Inclusive Education of Persons with Disabilities: The Policy and Practice Implications*, 12 *ASIA-PACIFIC J. HUM. RTS.* L. 1, 2, 34 (2011).

74 Resource implications have been used to lobby for enhanced access to digital content for students with print disabilities. There are massive resource and access differences between, on one hand, manually scanning a textbook, and on the other hand, obtaining a digital copy directly from publisher or from a database. Paul Harpur & Rebecca Loudoun, *The Barrier of the Written Word: Analysing Universities' Policies to Include Students with Print Disabilities and Calls for Reforms*, 33 *J. HIGHER EDUC. POL'Y & MGMT.* 153, 157, 165 (2011).

75 *See, e.g.*, Daily Editorial Board, *U Must Expand Classroom Access*, *THE MINNESOTA DAILY* (Mar. 8, 2016, 12:00 AM), <http://www.mndaily.com/article/2016/03/u-must-expand-classroom-access> (reporting that according to experts in educational design, the University of Minnesota is behind in shaping classrooms around a model of Universal Design).

students with disabilities.<sup>76</sup> Reasonable accommodations involve making alterations to environments to enable persons with disabilities to access opportunities and perform on an equal basis with others.<sup>77</sup> Professor Sir Bob Hepple explains that there are three broad categories of reasonable accommodations that need to be addressed in education.<sup>78</sup> The first category concerns changing modalities, for example, providing sign language interpreters or allowing extra time for examinations.<sup>79</sup> These adjustments make up a significant number of reasonable accommodation requests.<sup>80</sup> The second category focuses on changes in the built environment, such as the installation of ramps.<sup>81</sup> The third category concerns access to auxiliary aids, such as installing screen readers on computers.<sup>82</sup> To determine whether a proposed accommodation is reasonable, at least in the established American context, involves balancing the cost of the adjustments when compared to the resources of the duty holder, the impact of the accommodation on the duty holder, and the position and relationship of the place where the accommodation is to be made.<sup>83</sup>

Universities are obliged to follow the approach in the CRPD and the CRPD Committee's detailed *General Comment No. 4* to create

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76 CRPD, *supra* note 10, at art. 24(1), (2)(c). The Concluding Remarks of the Committee on the Rights of Persons with Disabilities can be instructive here. For example, the Concluding Remarks for Canada recommend that Canada "(a) Adopt, implement and oversee policies on inclusive and quality education throughout its territory; [and] . . . (d) Adopt a strategy for the provision of reasonable accommodation in schools and other learning institutions . . . ." Comm. on the Rights of Persons with Disabilities, Concluding Observations on the Initial Report of Canada, ¶ 44, U.N. Doc. CRPD/C/CAN/CO/1 (May 8, 2017). Similar suggestions were made in the concluding remarks for Australia on education. Comm. on the Rights of Persons with Disabilities, Concluding Observations on the Initial Report of Australia, Adopted by the Committee at its Tenth Session (2-13 September 2013), ¶ 46, U.N. Doc. CRPD/C/AUS/CO/1 (Oct. 21, 2013).

77 Anna Lawson, *Reasonable Accommodation and Accessibility Obligations: Towards a More Unified European Approach?*, 11 EUR. ANTI-DISCRIMINATION L. REV. 11-12 (2010).

78 BOB HEPPLER, *EQUALITY: THE LEGAL FRAMEWORK* 94-95 (2d ed. 2014).

79 *Id.*

80 Mary J. Ziegler & David Sloan, *Accessibility and Online Learning*, in *DISABILITY, HUMAN RIGHTS, AND INFORMATION TECHNOLOGY* 158 (Jonathan Lazar & Michael Ashley Stein eds., 2017) [hereinafter *INFORMATION TECHNOLOGY*].

81 See HEPPLER, *supra* note 78, at 94.

82 *Id.* at 95.

83 See Michael Ashley Stein, *The Law and Economics of Disability Accommodations*, 53 DUKE L.J. 79 (2003).

truly inclusive educational environments.<sup>84</sup> Moreover, ensuring universal design and universal design for learning as a matter of course can obviate the need for follow-up actions in the form of reasonable accommodations. Doing so is economical, more efficient, and less expensive.<sup>85</sup> It is also more just. If a disabling barrier can be designed out of the educational experience with reasonable effort, universities should adopt this approach, rather than requiring a student to meet and disclose their disability to administrative staff and their professors, and often have the existence and manifestations of their impairment exposed and discussed in public settings.<sup>86</sup> Moreover, universities should not be creating additional hurdles to educational success on those who are already forced to engage a greater number of educational and social issues than the wider student cohort.<sup>87</sup>

Some measures are expensive and require the built environment to be made accessible. While expensive, failing to enable all students to access the campus on an equal basis has resulted in students being unable to complete their studies alongside their peers and being forced to move schools.<sup>88</sup> Some of the measures that universities can adopt to create inclusive educational environments cost little or nothing to achieve, and require flexibility and creativity rather than equipment purchases or additional staffing.<sup>89</sup> Take, for example, the case of a student with scoliosis who can use only one type of standard issue chair.<sup>90</sup> When the student walked into the exam

84 See *supra* Section II.C.

85 See Michael Ashley Stein, *Same Struggle, Different Difference: ADA Accommodations as Antidiscrimination*, 153 U. PA. L. REV. 579 (2004).

86 For reflections and suggestions from a professor who has significant experience managing students with disabilities making requests for accommodations, see, for example, Gail A. Hornstein, *Why I Dread the Accommodations Talk*, THE CHRONICLE OF HIGHER EDUCATION (Mar. 26, 2017), <https://www.chronicle.com/article/Why-I-Dread-the-Accommodations/239571>.

87 Ravi Malhotra & Robin F. Hansen, *The United Nations Convention on the Rights of Persons with Disabilities and its Implications for the Equality Rights of Canadians with Disabilities: The Case of Education*, 29 WINDSOR Y.B. ACCESS JUST. 73, 74 (2011) (noting that disabling “barriers are evident in virtually every area of life: employment, transportation, housing, educational institutions and more.”).

88 See, e.g., *Commencement 2012: Hehir Presents Kevin Mintz with Diploma*, HARVARD GRADUATE SCHOOL OF EDUCATION (May 31, 2012, 12:08 PM), <https://www.gse.harvard.edu/news/12/05/commencement-2012-hehir-presents-kevin-mintz-diploma>.

89 Stein, *supra* note 83, at 184; Stein, *supra* note 85, at 585.

90 Rachel Whalen, *Overlooked and Unaddressed: Students Recount Fighting Ableism on Campus*, THE CORNELL DAILY SUN (Nov. 30, 2016), <http://cornellsun>.



room, already a situation of high pressure, she discovered that she could not sit in the assigned standard issued chair for a long period of time.<sup>91</sup> Her request for a chair change was greeted by hostility from fellow students; consequently she was socially intimidated to undergo the exam while likely distracted, upset, and in discomfort.<sup>92</sup>

Other disabling barriers are created by the conduct of professors, for example those who ban laptops in class.<sup>93</sup> This ban may be unsettling or annoying for many students, but is disabling for students with certain types of disabilities (for instance, visual impairment, Autism, or muscular-skeletal diseases) who need laptops to operate on an equal basis in a classroom setting.<sup>94</sup> To achieve laptop use, these students with disabilities must defend their right to university staff through formal processes, and often to other students via social interaction; if their disability is not readily apparent, these students have been forced to disclose their disability status.<sup>95</sup> This disclosure can result in students experiencing gratuitous stigma, differential treatment, discomfort, and privacy violations.<sup>96</sup>

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com/2016/11/30/overlooked-and-unaddressed-students-recount-fighting-ableism-on-campus/ (discussing ableism and support for students with disabilities at Cornell University).

91 *Id.*

92 *Id.*

93 Joanna Orland, *Technology Makes College Accessible for Students with Disabilities, but Only if Professors Allow It*, THE DAILY ORANGE (Oct. 1, 2017, 10:23 PM), <http://dailyorange.com/2017/10/assistive-technology-makes-college-accessible-students-disabilities-professors-allow/> (recounting impact on students with various disabilities at Syracuse University).

94 *See id.*

95 *See* Laurie Knis-Matthews et al., *The Meaning of Higher Education for People Diagnosed with a Mental Illness: Four Students Share Their Experiences*, 31 PSYCHIATRIC REHABILITATION J. 107, 113 (2007) (finding that students with psychiatric disabilities may be less inclined to disclose their diagnoses and not self-advocate for postsecondary disability accommodations due to fears of being stigmatized and victimized).

96 Mary Fletcher Pena, *Reevaluating Privacy and Disability Laws in the Wake of the Virginia Tech Tragedy: Considerations for Administrators and Lawmakers*, 87 N.C. L. REV. 305, 308 (2008) (constructing students with mental disabilities as a potential threat that requires management); Christina Yuknis & Eric R. Bernstein, *Supporting Students with Non-Disclosed Disabilities: A Collective and Humanizing Approach*, in DISABILITY AS DIVERSITY, *supra* note 50, at 3 (observing that students with disabilities may not disclose to universities); Elizabeth Wolnick, *Depression Discrimination: Are Suicidal College Students Protected by the Americans with Disabilities Act?*, 49 ARIZ. L. REV. 989, 1000 (2007) (observing that students with depression related disabilities run the risk of exclusion if they disclose their disability to administrators).

### C. *Information and Communication Technologies*<sup>97</sup>

Effective implementation of CRPD Article 24 requires that information and communication technologies utilized in university education be equally accessible to students with disabilities.<sup>98</sup> The article's text does not specifically enunciate this right, but it is inferred through the requirement that States Parties "ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning . . . on an equal basis with others."<sup>99</sup> *General Comment No. 4*, however, does specifically articulate this proposition by noting that "States parties must ensure that the rapid development of innovations and new technologies designed to enhance learning are accessible to all students, including those with disabilities."<sup>100</sup>

The right to access information and communication technologies in higher education is supported by other articles in the CRPD.<sup>101</sup> Prominently, CRPD Article 9 requires States Parties to ensure equal entry to this assistive technology as part of its mandate "[t]o enable persons with disabilities to live independently and participate fully in all aspects of life."<sup>102</sup> *General Comment No. 2*, which elaborates on Article 9 and the right to accessibility, observes that without "accessible information and communication, persons with disabilities would not have the opportunity to exercise their right to education."<sup>103</sup> *General Comment No. 2* elaborates further that States Parties are required to introduce positive duties into laws to incorporate and implement the principle of universal design,<sup>104</sup> which is likewise required by CRPD Article 4.<sup>105</sup>

The imperative for equally accessing information and communication technologies in higher education is reinforced by CRPD Article 21 on the right of freedom of expression and opinion, and access to information.<sup>106</sup> A central element of learning involves the transferring, analysis, and expression of information

97 Note: a portion of this section also appears in PAUL HARPUR, DISCRIMINATION, COPYRIGHT AND EQUALITY: OPENING THE E-BOOK FOR THE PRINT DISABLED 65 (2017).

98 See CRPD, *supra* note 10, at art. 24.

99 *Id.* at art. 24(5).

100 General Comment No. 4, *supra* note 32, ¶ 22.

101 See INFORMATION TECHNOLOGY, *supra* note 80, at 3.

102 CRPD, *supra* note 10, at art. 9.

103 General Comment No. 2, *supra* note 69, ¶ 39.

104 *Id.*

105 *Id.* ¶ 28.

106 CRPD, *supra* note 10, at art. 21. See also INFORMATION TECHNOLOGY, *supra* note 80, at 13–14.



and ideas. CRPD Article 21 requires that persons with disabilities have a “right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice.”<sup>107</sup> In turn, CRPD Article 2 defines communication to include information and communication technologies.<sup>108</sup> Reading the rights in Article 21 in conjunction with those enunciated in Articles 2 and 24, respectively, provides higher education students with disabilities with a strong claim to fully inclusive information and communication technologies.<sup>109</sup>

The CRPD-derived right to equally access information and communication technologies in higher education has been provided additional support through the World Intellectual Property Organization’s (WIPO) Treaty to Facilitate Access to Published Works for Persons Who Are Blind, Visually Impaired, or Otherwise Print Disabled (Marrakesh Treaty).<sup>110</sup> While the Marrakesh Treaty applies only to accessing books for the print disabled, it is significant for representing a weakening of intellectual property rights in favor of disability human rights.<sup>111</sup> It is exceptionally rare for WIPO to weaken intellectual property rights,<sup>112</sup> and so this move is having an impact globally on State and corporate practices.<sup>113</sup> The Marrakesh Treaty Preamble recognizes, *inter alia*, the “positive impact of new information and communication technologies” on the print disabled, and that the benefits from such technologies “may be reinforced by an enhanced legal framework at the international level.”<sup>114</sup> One way in which the Marrakesh Treaty facilitates equal access to information communication technologies is through Article 7, concerning technological protection measures that reduce persons

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107 CRPD, *supra* note 10, at art. 21.

108 *Id.* at art. 2.

109 *See generally* INFORMATION TECHNOLOGY, *supra* note 80.

110 Marrakesh Treaty to Facilitate Access to Published Works for Persons Who Are Blind, Visually Impaired, or Otherwise Print Disabled, *opened for signature* Jun. 28, 2013, WIPO Doc VIP/DC/8 (not yet in force) [hereinafter Marrakesh Treaty] art. 3; Jonathan Lazar & Michael Ashley Stein, *Introduction*, in INFORMATION TECHNOLOGY, *supra* note 80, at 150.

111 PAUL HARPUR, DISCRIMINATION, COPYRIGHT AND EQUALITY: OPENING THE E-BOOK FOR THE PRINT DISABLED 65 (2017).

112 Paul Harpur & Nic Suzor, *Copyright Protections and Disability Rights: Turning the Page to a New International Paradigm*, 36 U.N.S.W. L.J. 745, 761–68 (2013).

113 *See* LAURENCE R. HELFER ET AL., THE WORLD BLIND UNION GUIDE TO THE MARRAKESH TREATY: FACILITATING ACCESS TO BOOKS FOR PRINT-DISABLED INDIVIDUALS (2017).

114 Marrakesh Treaty, *supra* note 110.

with disabilities' use of adaptive technologies to access content. This article essentially requires States to permit persons with disabilities and their representatives to strip digital protections to enable persons with print disabilities to access content.<sup>115</sup> Students with print disabilities' access to textbooks is a classic example of how strategic approaches by universities can promote ability equality.<sup>116</sup> For decades textbooks were inaccessible for millions of print disabled students across the globe.<sup>117</sup> Use of digital technology by publishing houses has now, and will continue even more in the future, to drastically shift that access.<sup>118</sup>

Digital access can be grouped by technologies that the university controls and those that they obtain from external parties such as laptops, clickers, or software.<sup>119</sup> Crucially, the digital space can be dramatically enabling or extremely disabling,<sup>120</sup> with universally designed technologies providing the best opportunity for reaching all students.<sup>121</sup> Consider by contrast the highly negative experience of a Dartmouth undergraduate who was granted access to Echo360 technology in order to take class notes only after suing the university.<sup>122</sup>

Jonathan Lazar, Daniel F. Goldstein, and Anne Taylor suggest

115 HARPUR, *supra* note 111.

116 Paul Harpur, *Ensuring Equality in Education: How Australian Laws are Leaving Students with Print Disabilities Behind*, 15 MEDIA & ARTS L. REV. 70, 81 (2010); Paul Harpur & Rebecca Loudoun, *The Barrier of the Written Word: Analysing Universities' Policies to Include Students with Print Disabilities and Calls for Reforms*, 33 J. HIGHER EDUC. POL'Y & MGMT. 153, 153 (2011).

117 General Comment No. 4, *supra* note 32, ¶ 22.

118 See Paul Harpur & Nicolas Suzor, *The Paradigm Shift in Realising the Right to Read: How eBook Libraries are Enabling in the University Sector*, 29 DISABILITY & SOC'Y. 1658 (2014).

119 INFORMATION TECHNOLOGY, *supra* note 80, at 159.

120 For example, E-Books can enable persons with print disabilities to access literally millions of titles, unless E-libraries are structured to prevent disability inclusion. Paul Harpur & Nicolas Suzor, *Copyright Protections and Disability Rights: Turning the Page to a New International Paradigm*, 36 U.N.S.W. L.J. 745, 747–50 (2013); Paul Harpur & Nicolas Suzor, *Discrimination: From Braille Books to Bookshare*, 13 MEDIA & ARTS L. REV. 1, 2–4 (2008).

121 Paul Harpur & Nicolas Suzor, *The Paradigm Shift in Realising the Right to Read: How eBook Libraries are Enabling in the University Sector*, 29 DISABILITY & SOC'Y. 1658 (2014); Paul Harpur, *From Universal Exclusion to Universal Equality: Regulating Ableism in a Digital Age*, 40 N. KY. L. REV. 529, 539 (2013).

122 Julian Nathan, *Student Sues College over Disability Accommodations*, THE DARTMOUTH (Apr. 27, 2017, 2:15 AM), <http://www.thedartmouth.com/article/2017/04/student-sues-college-over-disability-accommodations>.

two measures that can be easily adopted by universities.<sup>123</sup> The first measure is to adopt a policy of compliance monitoring. Compliance monitoring involves “proactively investigating, monitoring, and ensuring accessibility . . . .”<sup>124</sup> By continually monitoring processes, universities can identify when upgrades and existing processes can create barriers to disability inclusion. Once barriers are identified, then fixes should be mainstreamed to reduce the risk of disabling barriers occurring.<sup>125</sup> Many decisions around inclusion or exclusion are made without the decision maker even knowing about the options. For example, when a person designs their PowerPoint for staff and student presentations they can use a template that is difficult for students with certain disabilities to utilize. Information technology specialists should identify this problem and proactively set as the default setting PowerPoint templates that are inclusive of more people. As work spaces become less disabling, the productivity of workers with disabilities is increased and the need for reasonable accommodations is reduced.<sup>126</sup>

Another measure proposed by Lazar, Goldstein, and Taylor involves embracing disability inclusive procurement practices.<sup>127</sup> Lazar, Goldstein and Taylor provide examples of universities and others who have placed obligations in procurement contracts that suppliers demonstrate they have embraced universal design, and that place a duty on the supplier to remedy disabling barriers where such barriers arise.<sup>128</sup> This process reduces the burden on universities and increases the probability that suppliers will factor in universal design in products, thereby reducing disabling barriers in society.<sup>129</sup>

Technological advancements have transformed the role of libraries and their capacity to provide greater inclusion for persons with disabilities.<sup>130</sup> Mass “digitization facilitates the conversion of books to audio and tactile formats, increasing access for individuals

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123 JONATHAN LAZAR ET AL., ENSURING DIGITAL ACCESSIBILITY THROUGH PROCESS AND POLICY 161 (2015).

124 *Id.*

125 *Id.*

126 *Id.*

127 *Id.* See also Michael Ashley Stein & Penelope Stein, *Beyond Disability Civil Rights*, 58 HASTINGS L.J. 1203 (2007).

128 LAZAR ET AL., *supra* note 123, at 161.

129 *Id.* at 1–2. For an exhaustive treatment, see CHRISTOPHER MCCRUDDEN, BUYING SOCIAL JUSTICE: EQUALITY, GOVERNMENT PROCUREMENT AND LEGAL CHANGE (2007).

130 Paul T. Jaeger et al., *The Intersection of Human Rights, Social Justice, the Internet, and Accessibility in Libraries: Access, Education, and Inclusion*, in INFORMATION TECHNOLOGY, *supra* note 80, at 58–59.

with disabilities.”<sup>131</sup> University libraries across the globe have been exceptionally active in digitizing their collections to enhance access to works. University libraries are taking a leading role in creating networks to maximize students with print disabilities access to the written word.<sup>132</sup>

Google has led one of the largest mass digitization operations in history.<sup>133</sup> In 2004, Google reached an agreement with the Bodleian library at the University of Oxford to digitize the library’s one million 18th century works not restricted by copyright laws.<sup>134</sup> Later in 2004, the Google Print Library Project was launched with the support of Harvard University, the University of Michigan, the New York Public Library, Oxford University, and Stanford University.<sup>135</sup> Under the Google Print Library Project, Google undertook to perform mass digitization of the 15 million works owned by these institutions.<sup>136</sup> In 2005, the Google Print Library Project expanded to accept partners from Belgium, France, Germany, Italy, the Netherlands, Spain, and Switzerland.<sup>137</sup> In 2005, the Google Print Library Project was branded the Google Books project.<sup>138</sup>

The Google Books mass digitization project included over five million works that were not covered by copyright, and included works where rights-holders had granted permission. The digitization of such works complied with copyright laws and was not contested.<sup>139</sup> The project, however, included millions of works that were regulated by copyright laws; Google announced that it would borrow 30 million works from participating libraries and that it intended to scan 25 million works that were protected by copyright.<sup>140</sup> Google argued that exceptions to copyright permitted

131 *The Authors Guild, Inc. v. Google, Inc.*, 954 F. Supp. 2d 282, 288 (S.D.N.Y. 2013) (citing a letter from Marc Maurer, President of the Nat’l Fed’n for the Blind, to J. Michael McMahon, Office of the Clerk (Jan. 19, 2010)).

132 Paul Harpur, *My Experience and the Experience of Millions*, HATHITRUST: PERSPECTIVES FROM HATHITRUST (May 24, 2017), <https://www.hathitrust.org/blogs/perspectives-from-hathitrust/my-experience-and-experience-of-millions>.

133 Hannibal Travis, *Estimating the Economic Impact of Mass Digitization Projects on Copyright Holders: Evidence from the Google Book Search Litigation*, 57 J. COPYRIGHT SOC’Y USA 907, 907 (2009).

134 HARPUR, *supra* note 111, at 135–42.

135 *Id.*

136 *Id.* at 135.

137 *Id.*

138 *Id.* at 135–42.

139 *Id.*

140 *Id.* at 139. *See generally* *The Authors Guild v. Google, Inc.*, 770 F. Supp. 2d 666

Google to make derivative digital copies of works.<sup>141</sup> Rights-holders disagreed, though importantly for students with print disabilities, the ultimate settlement has enabled them to continue to access copyright-protected works scanned by Google as part of an exception to United States copyright laws.<sup>142</sup>

Using primarily the Google Books digitization project, the Hathitrust E-Library has over 16 million E-Books in the library.<sup>143</sup> The Hathitrust is a not-for-profit trust controlled by a collective of universities libraries across the globe.<sup>144</sup> The Hathitrust has over 100 individual university and university groups as partner libraries.<sup>145</sup> This list includes highly prestigious institutions, including all Ivy League universities and other highly ranked United States universities, including Boston University, Duke University, Emory University, Massachusetts Institute of Technology, New York University, Syracuse University, and the University of California, to name a few; Canadian universities including McGill University, and University of British Columbia, the University of Queensland from Australia, and Universidad Complutense de Madrid from Europe.<sup>146</sup> The Hathitrust operates the Hathitrust universal library, which enables staff and students associated with partner libraries to search and download digital copies of works.<sup>147</sup> While the operation of copyright has reduced the capacity of Google and the Hathitrust to expand access to the written word, the historic and continuing involvement of university libraries illustrates that there is strong interest in some elements of this sector to promote inclusive education.

#### **D. Extra-Curricular Activities**

As part of its mandate for life-long education, CRPD Article 24

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(S.D.N.Y. 2011).

141 Jonathan Band, *Symposium: Collective Management of Copyright: Solution or Sacrifice?: The Book Rights Registry in the Google Book Settlement*, 34 COLUM. J.L. & ARTS 671, 671-72 (2011).

142 PETER BLANCK, *EQUALITY: THE STRUGGLE FOR WEB ACCESSIBILITY BY PERSONS WITH COGNITIVE DISABILITIES* 191-94 (2014); Authors Guild, Inc. v. HathiTrust, 755 F.3d 87 (2d Cir. 2014).

143 Mike Furlough, *Hathitrust Has Reached 16 Million Volumes*, HATHITRUST <https://www.hathitrust.org/16-million-volumes> (last visited Jan. 9, 2018).

144 Jeremy York, *Building a Future by Preserving Our Past: The Preservation Infrastructure of HathiTrust Digital Library*, HATHITRUST (Jun. 7, 2010), <https://www.hathitrust.org/documents/hathitrust-ifla-201008.pdf>.

145 *Partnership Community*, HATHITRUST (last visited Jan. 8, 2017) <http://www.hathitrust.org/community>.

146 *Id.*

147 Harpur, *supra* note 132.

promotes the development of the full “human potential and sense of dignity and self-worth” of persons with disabilities.<sup>148</sup> Consequently, the right to inclusive higher education is not circumscribed by participation in or completion of a particular course, nor is it limited to formal educational modules.<sup>149</sup> Accordingly, universities can play an important role by supporting engagement by students with disabilities in activities that advance their learning and development beyond the classroom.

The role of the State and universities in creating disability-inclusive extra-curricular activities is more complex than purely curricular activities. Extra-curricular activities technically do not form a formal part of students’ education because they do not engender credit towards completing a course, and these activities can also involve various external parties outside the control of universities. Thus, although some extra-curricular activities are conducted by universities with or without financial support (e.g., drama societies or cultural-based interest groups),<sup>150</sup> students might also volunteer at community-based programs (such as public interest law firms or senior centers) that are separate from universities.<sup>151</sup> Within the latter circumstance, most extra-curricular activities involve parties that operate under different legal and theoretical paradigms from those found in the publically-based education sector.<sup>152</sup> Moreover, CRPD Article 30’s right to participate in cultural, recreational, and sporting activities differs from that of Article 24. Article 24 provides that States Parties “shall ensure” education, while Article 30 is cast as a lesser duty—that States Parties “shall take all appropriate

148 CRPD, *supra* note 10, at art. 24(1)(a).

149 *See generally* General Comment No. 4, *supra* note 32.

150 Katherine C. Aquino et al., *Does Disability Matter?: Students’ Satisfaction with College Experiences*, in *DISABILITY AS DIVERSITY*, *supra* note 50, at 47–60 (observing that while academic and social integration both occur within the same postsecondary environment, academic integration focuses on students’ academic performance, ability to endure educational demands, and achieve academic goals, while social integration refers to students’ involvement with activities and developing social interactions and networks).

151 Francina Cantatore, *Boosting Law Graduate Employability: Using a Pro Bono Teaching Clinic to Facilitate Experiential Learning in Commercial Law Subjects*, 25 *LEGAL EDUC. REV.* 14 (2015); Monica Taylor & Clare Cappa, *Student Pro Bono and its Role in Contemporary Australian Law Schools*, 41 *ALTERNATIVE L.J.* 121 (2016).

152 For a discussion of the CRPD right to engage in cultural, recreational, and sporting activities, see Janet E. Lord & Michael Ashley Stein, *Social Rights and the Relational Value of the Rights to Participate in Sport, Recreation, and Play*, 27 *B.U. INT’L L.J.* 249 (2009).



measures.”<sup>153</sup>

Nevertheless, when extra-curricular activities are engaged in by students of the university (consider a university-organized delegation in a walk against hunger), and in particular with university support (for instance, busing to a State capital to lobby the legislature against cuts to student financial aid), then Article 24 operates to increase universities' obligations to facilitate participation in such activities.<sup>154</sup> Moreover, educational scholars confirm the importance of extra-curricular activities,<sup>155</sup> and some courts have accepted that students' education would “sustain irreparable harm” if they were not provided the opportunity to participate in extra-curricular activities.<sup>156</sup> At the same time, and despite the obligation to take all appropriate measures to accommodate students with disabilities in extra-curricular activities, this duty has not yet been appropriately reflected in law or practice.<sup>157</sup> Examples abound of campus clubs not accommodating students with disabilities,<sup>158</sup> elevators to student social events not being wheelchair accessible or breaking down,<sup>159</sup> and students being unable to visit with friends in their accommodations

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153 CRPD, *supra* note 10, at arts. 24, 30.

154 See generally General Comment No. 4, *supra* note 32.

155 Mary H. Bluehardt & Roy J. Shephard, *Using an Extracurricular Physical Activity Program to Enhance Social Skills*, 28 J. LEARNING DISABILITIES 160 (1995); W. E. Carter et al., *What Are You Doing After School? Promoting Extracurricular Involvement for Transition-age Youth with Disabilities*, 45 INTERVENTION IN SCHOOL & CLINIC 275 (2010); David Haycock & Andy Smith, *Still 'More of the Same for the more Able?' Including Young Disabled People and Pupils with Special Educational needs in Extra-curricular Physical Education*, 16 SPORT, EDUCATION & SOC'Y 507 (2011); Harold L. Kleinert et al., *Including Students with Moderate and Severe Disabilities in Extracurricular and Community Recreation Activities: Steps to Success*, 39 TEACHING EXCEPTIONAL CHILDREN 33 (2007).

156 See, e.g., *Cruz ex rel. Cruz v. Pennsylvania Inters. Athletic*, 157 F. Supp. 2d 485, 500 (E.D. Pa. 2001) (discussing sport).

157 Ian Forster, *Fair Play for Those Who Need It Most: Athletic Opportunities for High School Student Athletes with Disabilities*, 22 JEFFREY S. MOORAD SPORTS L.J. 693, 693 (2015) (arguing there is a lack of sporting opportunities for students with disabilities).

158 Black, *supra* note 60.

159 Meara Isenberg, *UTA Students with Disabilities Story is Told through Exhibit*, THE DAILY TEXAN (Oct. 16, 2017), <http://www.dailytexanonline.com/2017/10/16/uta-students-with-disabilities-story-is-told-through-exhibit>; Angie Baldelomar, *Accessibility Measures on Campus Need Improvements, People with Disabilities Say*, THE U. DAILY KANSAN (Mar. 5, 2017), [http://www.kansan.com/news/accessibility-measures-on-campus-need-improvements-people-with-disabilities-say/article\\_0863da3c-01ed-11e7-a9c0-3b156315327e.html](http://www.kansan.com/news/accessibility-measures-on-campus-need-improvements-people-with-disabilities-say/article_0863da3c-01ed-11e7-a9c0-3b156315327e.html).

or join them at cultural events.<sup>160</sup>

When community spaces are not accessible by students with disabilities, they are excluded and can feel as though they are not part of the university community.<sup>161</sup> A pointed example was reported by a Kansas University student unable to attend a presentation given by a friend due to lack of awareness about wheelchair access.<sup>162</sup> Similar situations, examples of which are abound,<sup>163</sup> signal to students, academics, staff, and visitors to university campuses that they are welcome, but only if they can figure out how to manage a disabling environment.<sup>164</sup>

### ***E. Hiring Academic and Other Staff with Disabilities***

As noted throughout, universities are bound by CRPD Article 24's inclusive higher education mandate. By the same token, States Parties—and inter alia universities—must ensure that persons with disabilities are employed in the public sector, due to CRPD Article 27.<sup>165</sup> Specifically, Article 27 acknowledges the right of persons with disabilities to gain a living by engaging in “work freely chosen or accepted in [an open] labor market,” with an ambient work environment that is inclusive of and accessible to people with disabilities.<sup>166</sup> To achieve these standards, employers, including universities, must, at a minimum, prohibit discrimination on the basis of disability with regard to the entirety of matters “concerning all forms of employment, including conditions of recruitment, hiring

160 See Posnova, *supra* note 57, at 5.

161 Kasturi Pananjady, ‘Grading the Green’ Assesses Accessibility of Campus Buildings, THE BROWN DAILY HERALD (Dec. 2, 2015), <http://www.browndailyherald.com/2015/12/02/grading-the-green-assesses-accessibility-of-campus-buildings/>.

162 Angie Baldelomar, *Accessibility Measures on Campus Need Improvements, People with Disabilities Say*, THE U. DAILY KANSAN (Mar. 5, 2017), [http://www.kansan.com/news/accessibility-measures-on-campus-need-improvements-people-with-disabilities-say/article\\_0863da3c-01ed-11e7-a9c0-3b156315327e.html](http://www.kansan.com/news/accessibility-measures-on-campus-need-improvements-people-with-disabilities-say/article_0863da3c-01ed-11e7-a9c0-3b156315327e.html).

163 See, e.g., Valerie Piro, *Applying to College as a Wheelchair User*, INSIDE HIGHER ED (Apr. 6, 2017), <https://www.insidehighered.com/views/2017/04/06/challenges-wheelchair-users-face-when-visiting-colleges-essay>; Perrine Ausseil et al., *BC Cited by State Agency for Disability Discrimination*, THE HEIGHTS (May 5, 2016), <http://bcheights.com/2016/05/05/bc-cited-state-agency-disability-discrimination/>.

164 See Lydia Lum, *Silvers Continues to Lead Way for Disabled*, DIVERSE ISSUES IN HIGHER EDUC. (April 26, 2017), <http://diverseeducation.com/article/95794/> (disability rights icon Anita Silvers likened inaccessible higher education to “telling disabled students, ‘You are not worthy of college’”).

165 CRPD, *supra* note 10, at art. 27(1)(g).

166 *Id.* at art. 27.



and employment, continuance of employment, career advancement, and safe and healthy working conditions.”<sup>167</sup> Furthermore, universities as employers must “enable persons with disabilities to have effective access to general technical and vocational guidance programs,”<sup>168</sup> and ensure that reasonable accommodation is provided to persons with disabilities.<sup>169</sup>

Unfortunately, many universities are not meeting the standard set out in the CRPD to be inclusive as employers.<sup>170</sup> Considering the range of incidental rights associated with the right to work, it is beyond this paper to analyze all the positive and negative aspects of disability inclusion in the university sector (although we will turn to student internships in the next section). For now, we note a few key challenges confronting workers with disabilities in the university sector. First are the often-unaddressed discriminatory attitudes. Potential faculty with disabilities are deterred from certain institutions due to perceptions of campus climate.<sup>171</sup> Relatedly, those with not easily discernable impairments, such as mental health issues, are reluctant to disclose and access accommodations.<sup>172</sup> Moreover, accessible learning spaces are not always accessible teaching spaces. Both authors have experienced the phenomenon of classrooms that are deemed “accessible” but that contain inaccessible podiums or controls for academics with disabilities.<sup>173</sup> Where universal design has not been adopted, universities, as employers, attract duties to make reasonable accommodations.<sup>174</sup> However, many universities fund their disability-related accommodations in a manner that is

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167 *Id.* at art. 27(1)(a).

168 *Id.* at art. 27(1)(d).

169 *Id.* at art. 27(1)(i).

170 Sadly, the same is true of American law schools which have uniformly ignored their legal four-decade obligations under the Rehabilitation Act to engage in affirmative action hiring, including academic instructors. See Leslie Pickering Francis & Anita Silvers, *No Disability Standpoint Here!: Law School Faculties and the Invisibility Problem*, 69 U. PITT L. REV. 499, 506–07 (2008).

171 See D. Fuecker & W. S. Harbour, *UReturn: University of Minnesota Services for Faculty and Staff with Disabilities*, 154 NEW DIRECTIONS FOR HIGHER EDUC. 45 (2011).

172 M. Price et al., *Disclosure of Mental Disability by College and University Faculty: The Negotiation of Accommodations, Supports, and Barriers*, 37 DISABILITY STUD. Q. (2017), <http://dsq-sds.org/article/view/5487/4653>.

173 M. Damiani & W. Harbour, *Being the Wizard Behind the Curtain: Teaching Experiences of Graduate Teaching Assistants with Disabilities at U.S. Universities*, 40 INNOVATIVE HIGHER EDUC. 399, 405 (2015).

174 E. Goldstein, *Applications of Universal Design to Higher Education Facilities*, in UNIVERSAL DESIGN IN HIGHER EDUCATION: FROM PRINCIPLES TO PRACTICE 199, 210-11 (S. E. Burgstahler ed., 2d ed. 2015).

directed exclusively to students; as a result, persons with disabilities become less attractive to deans and heads of schools as potential academic or staff hires, since accommodation costs, if they exist, will need to be funded out of their own departmental budgets.<sup>175</sup>

Universities can enable disability-inclusion by doing more than simply removing obvious barriers. Employing academics and staff members with disabilities can transform the lives of those who are employed, as well as having wider transformational implications. Mentors and role models are important for everyone, but even more so for marginalized populations, such as people with disabilities.<sup>176</sup> Students with disabilities often need to operate differently than the wider student cohort. Being an outsider can have practical challenges, such as how to find a means to manage disabling barriers, as well as emotional challenges.<sup>177</sup> For example, mentors and role models with disabilities can play an important and empowering role in the development and aspirations of students with disabilities—even in the face of social and familial naysayers.<sup>178</sup> Indeed, the singular importance of role models with disabilities has led to developing resources<sup>179</sup> and calls for the development of databases of disabled alumni, disability-friendly mentors, and job seekers with disabilities.<sup>180</sup>

Employing persons with disabilities across universities can also help combat prejudice in the wider workforce. Contact theory explains that a person is less prejudiced against a person with a particular attribute once they have had positive conduct with a person who has that particular attribute.<sup>181</sup> Primary research supports contact theory, finding that contact with a person with a disability was more efficacious in changing attitudes than only

175 NANCY J. EVANS ET AL., *DISABILITY IN HIGHER EDUCATION: A SOCIAL JUSTICE APPROACH* 207 (2017).

176 There is a distinction between mentors with disabilities and people who provide higher level of support. Dennis Rizzo, *With a Little Help From my Friends: Supported Self-Employment for People with Severe Disabilities*, 17 (2) J. VOCATIONAL REHABILITATION 97, 101 (2002).

177 Robert Wilton, *Workers with Disabilities and the Challenges of Emotional Labour*, 23 DISABILITY & SOC'Y 361, 371 (2008) (exploring the implications of emotional labor for workers with disabilities).

178 See Paul Harpur, *Naming, Blaming and Claiming Ablism: The Lived Experiences of Lawyers and Advocates with Disabilities*, 29 DISABILITY & SOC'Y 1234 (2014).

179 See, e.g., STEPHANIE L. ENYART ET AL., *LAWYERS, LEAD ON: LAWYERS WITH DISABILITIES SHARE THEIR INSIGHTS* (2011).

180 Carrie Griffin Basas, *Indulgent Employment? Careers in the Arts for People with Disabilities*, 40 RUTGERS L.J. 613, 637 (2009).

181 See Elizabeth F. Emens, *Intimate Discrimination*, 122 HARV. L. REV. 1307 (2009).

information provision.<sup>182</sup> Academics with disabilities have contact with hundreds of students each year in a power relationship that communicates volumes about the capacity of people with impairments.<sup>183</sup> After being lectured by a professor with a particular disability, it is probable that that student will be less likely to discriminate against a person with that attribute after graduation.<sup>184</sup>

#### **F. Facilitating Transitions to Work**

The right to lifelong education in CRPD Article 24 has several purposes, one of which is to enable persons with disabilities to participate effectively in society.<sup>185</sup> To participate effectively in society requires persons with disabilities to be part of society and to not be discounted as citizens.<sup>186</sup> Full citizenship is only possible when a person can exercise economic rights, and work is the way in which most people become economic actors.<sup>187</sup> While rights, laws and policies concerning education and work can be relegated to silos, the realization of the rights to education and work requires support in transitioning from full-time student to full-time worker.<sup>188</sup>

Research analyzing why persons with disabilities are not succeeding in the labor market often focuses upon how persons with disabilities can be supported to operate in a disabling labor market,<sup>189</sup> the role of strategic company policies and the thinking of

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182 Pheroza Daruwallaand & Simon Darcy, *Personal and Societal Attitudes to Disability*, 32 ANNALS OF TOURISM RESEARCH 549, 549 (2005).

183 Paul Harpur, *Combating Prejudice in the Workplace with Contact Theory: The Lived Experiences of Professionals with Disabilities*, 34 DISABILITY STUD. Q. (2014), <http://dsq-sds.org/article/view/4011/3544>.

184 Reiko Hayashi & Gary E. May, *The Effect of Exposure to a Professor with a Visible Disability on Students' Attitudes toward Disabilities*, 10 J. SOC. WORK IN DISABILITY & REHABILITATION 36 (2011) (finding that there is a statistically significant difference between students who had a professor with a disability and those who did not; the former had more positive attitudes toward disability); Lynnaire Sheridan & Suzanne Kotevski, *University Teaching with a Disability: Student Learnings Beyond the Curriculum*, 18 INT'L J. INCLUSIVE EDUC. 1162 (2014) (finding that students gain new experiences and gained additional learning by being taught by an academic with a disability).

185 CRPD, *supra* note 10, at art. 24(1)(c).

186 See CIVIL DISABILITIES: CITIZENSHIP, MEMBERSHIP, AND BELONGING 9–10 (Nancy J. Hirschmann & Beth Linker eds., 2015); JUDITH SHKLAR, AMERICAN CITIZENSHIP: THE QUEST FOR INCLUSION 3 (1991).

187 See Philip Alston, *Making Economic and Social Rights Count: A Strategy for the Future*, 68 POL. Q. 188, 191 (1997); Heymann et al., *supra* note 5.

188 Frank R. Rusch, et al., *Transition from School to Work: New Directions for Policy and Practice*, in DISABILITY AND EQUITY, *supra* note 5, at 197–208.

189 See PETER WATERHOUSE ET AL., NAT'L CTR. FOR VOCATIONAL EDUC.

line managers and human resource professionals,<sup>190</sup> and how those perspectives can be made more disability-inclusive.<sup>191</sup> While all these areas of research are important, one area that requires additional attention is why students with disabilities are not able to translate their educational success into meaningful work.<sup>192</sup>

The education process has an instrumental purpose beyond its inherent intellectual pleasure and social networking: the development of students' human capital for gainful employment. Embracing this notion, Professor Frank Rusch and colleagues asked whether the education of students with disabilities has "resulted in individuals acquiring better jobs, experiencing a higher quality of life, and encountering new opportunities for membership in the mainstream of society?"<sup>193</sup> Statistics across the globe are showing students with disabilities increasingly succeeding in primary and secondary studies but unable to translate their educational success into labor market success.<sup>194</sup> For instance, the United States Department of Labor's Office of Disability collects data on persons with a disability and has found that for all educational attainment groups, jobless rates for persons with a disability are higher than those for persons without a disability.<sup>195</sup> Considering education is

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RESEARCH, WHAT WOULD IT TAKE? EMPLOYER PERSPECTIVES ON EMPLOYING PEOPLE WITH A DISABILITY 3 (2010).

- 190 Susanne M. Bruyère & Sara A. Van Looy, *Finding and Maintaining Employment: Lessons from Workplace Nondiscrimination Measures in High-Income Countries, in DISABILITY AND EQUITY*, *supra* note 5, at 51–56.
- 191 Stephen Clayton et al., *Effectiveness of Return-to-work Interventions for Disabled People: A Systematic Review of Government Initiatives Focused on Changing the Behaviour of Employers*, 22 EUR. J. PUB. HEALTH 434, 435 (2012).
- 192 Stephanie Kacoyanis, *Seeing Past Disabilities in the Job Search*, HARV. GAZETTE (Nov. 28, 2016), <https://news.harvard.edu/gazette/story/2016/11/seeing-past-disabilities-in-the-job-search/> (reporting that "46 percent of disabled people in the U.S. rated their last experience applying for a job online as 'difficult to impossible' . . . [and] that the vast majority of disabled job seekers do not even reach the interview stage, despite having the education and skills to qualify them for a range of jobs. As a result, the unemployment rate for Americans with disabilities was 10.7 percent in 2015 — more than twice the rate for those with no disability (5.3 percent).").
- 193 Rusch et al., *supra* note 188, at 197.
- 194 See, e.g., Stephen Winn & Ian Hay, *Transition from School for Youths with a Disability: Issues and Challenges*, 24 DISABILITY & SOC'Y 103 (2009); *Disability, Vocation, and Education Training*, 2009 AUSTRALIAN BUREAU OF STAT. (Jun. 3, 2011), <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/4438.0Main%20Features62009> (Australian Bureau of Statistics reporting on this trend).
- 195 See *Economic News Release: Persons with a Disability: Labor Force Characteristics Summary*, U.S. DEP'T OF LABOR, BUREAU OF LABOR STATISTICS (Jun. 21, 2017), <https://www.bls.gov/news.release/disabl.nr0.htm>.

being used as one means to address the considerable employment gap between persons with disabilities (who have an unemployment rate of 10.5%), and the wider United States population (who have an unemployment rate of 4.6%), the failure of educated job seekers with disabilities to obtain work is a considerable concern.<sup>196</sup> There exists a rich body of work analyzing transitions for persons with disabilities between stages of education and from education to work.<sup>197</sup>

The level of assistance students with disabilities will require to transition into professionals with disabilities will depend on factors including the nature of a student's impairment and the profession they seek to enter. In many cases, students with disabilities that receive inadequate support in transitioning from education to work will have their career prospects reduced.<sup>198</sup> There are a range of activities students engage in to facilitate their successful transition from student to professional. Students with disabilities who are seeking to make this transition usually seek to engage in the same activities, as well as additional measures to best manage their impairment in the competitive professional environment.<sup>199</sup> Participating in industry-relevant volunteer or paid activities builds skills and can demonstrate to potential employers that the student is motivated and capable.<sup>200</sup> For this reason, aspiring professionals engage in paid and unpaid internships.<sup>201</sup> Internships and other

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196 *Id.*

197 *See, e.g.,* Frank R. Rusch et al., *Toward Self-Directed Learning, Post-High School Placement, and Coordinated Support: Constructing New Transition Bridges to Adult Life*, 32 CAREER DEV. FOR EXCEPTIONAL INDIVIDUALS 53 (2009); Theresa Severance & Pamela Starr, *Beyond the Classroom: Internships and Students with Special Needs*, 39 TEACHING SOC. 200 (2011).

198 *See, e.g.,* Helen Storr, et al., *Supporting Disabled Student Nurses from Registration to Qualification: A Review of the United Kingdom (UK) Literature*, 31 NURSE EDUC. TODAY 29 (2011).

199 Mary Schaefer Enright et al., *Career and Career-related Educational Concerns of College Students with Disabilities*, 75 J. COUNSELING & DEV. 103, 103-04 (1996).

200 Jack Gault et al., *Undergraduate Business Internships and Career Success: Are They Related?*, 22 J. MKTG. EDUC. 45, 51 (2000); Doug Risner, *Research, Design, and Implementation of an Internship Course in Dance: Turning Student Knowledge into Professional Know-How*, 15 J. DANCE EDUC. 60 (2015).

201 The employment status, and the entitlement to wages, remains an unsettled area of law. Madiha M. Malik, *The Legal Void of Unpaid Internships: Navigating the Legality of Internships in the Face of Conflicting Tests Interpreting the FLSA*, 47 CONN. L. REV. 1183 (2015) (analysing how recent lawsuits have brought the legality of unpaid internships under scrutiny); David C. Yamada, "Mass Exploitation Hidden in Plain Sight": *Unpaid Internships and the Culture of Uncompensated Work*, 52



forms of experiential learning can be more important for students with disabilities as greater questions about their capacity to work arise.<sup>202</sup>

Some of the activities involved in transitioning from student to professional are optional, while others are mandatory.<sup>203</sup> A number of professional bodies and qualifications require students to successfully complete a practical component as a condition precedent to entry or graduation.<sup>204</sup> While some of these placements can occur as part of employment, and unrelated to educational institutions, tertiary degrees in accountancy, dentistry, law, medicine, nursing, physiotherapy, and social work all involve industry-based practical work as a condition precedent to gaining tertiary qualifications.<sup>205</sup>

Universities can level the post-university employment playing field by working with professional bodies to clarify and resolve barriers to entry for various impairments. Many professional bodies are already active in this space,<sup>206</sup> however, universities have

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IDAHO L. REV. 937, 937 (2016) (“gaining internship experience has become a largely expected rite of passage for those seeking entry into many professions and vocations, until recently the legal implications of unpaid internships remained something of a sleeping giant.”).

202 Lori W. Briel & Elizabeth Evans Getzel, *Internships in Higher Education Promoting Success for Students with Disabilities*, 21 DISABILITY STUD. Q. (2001), <http://dsq-sds.org/article/view/254/257>.

203 See, e.g., James H. Backman & Cory S. Clements, *Significant but Unheralded Growth of Large Externship Programs*, 28 BYU J. PUB. L. 145 (2013).

204 While you do not need practical training to be admitted as an attorney in most United States jurisdictions, most law students engage in internships between their second and third years. In other jurisdictions around the world, such as Australia, practical experience working in the law is required prior to admission as a lawyer. See, e.g., Na’ama Landau, *Quickest Pathways to Becoming a Lawyer Around the World*, CRIMSON EDUCATION, <https://blog.crimsoneducation.org/blog/becoming-a-lawyer> (last visited May 5, 2018).

205 The Therapeutics Graduate Program and the MD-MBA Program at Harvard University have both required internships. See *Medical Education Student Handbook 5.04 MD-MBA Program*, HARV. MED. SCHOOL, <https://medstudenthandbook.hms.harvard.edu/504-md-mba-program-harvard-business-school> (last visited Dec. 29, 2017); *Required Curricula for the Therapeutics Graduate Program*, HARV. PROGRAM IN THERAPEUTIC SCI., <http://hits.harvard.edu/the-program/therapeutics-graduate-program/curriculum/> (last visited Dec. 29, 2017).

206 For example, the ABA Commission on Disability Rights aims “to promote the ABA’s commitment to justice and the rule of law for persons with mental, physical, and sensory disabilities and to promote their full and equal participation in the legal profession.” *About Us*, ABA COMMISSION ON DISABILITY RTS., [https://www.americanbar.org/groups/disabilityrights/about\\_us.html](https://www.americanbar.org/groups/disabilityrights/about_us.html) (last visited Dec. 8, 2017). This remains a challenging area and the National Conference of Bar Examiners (NCBE) has created unlawful

substantially more research and policy expertise than professional bodies that can be used to maximize human rights outcomes. Moreover, collaborative projects between professional associations and universities can develop informed responses to ability diversity and help find innovative strategies to reduce the negative impact of impairment on the working lives of people attempting to exercise their right to work.

Although educators provide support to students with disabilities on placements, there are reports that this support is sometimes inadequate, or that placement is difficult to complete due to the particular impairment in question.<sup>207</sup> Educational institutions and host industry partners can reduce disability inclusion by failing to actively identify and resolve access barriers before they disable the student.<sup>208</sup> While disability and equity officers deal with high numbers of students with disabilities, placement officers often have little to no experience with students or professionals with disabilities.<sup>209</sup> This lack of experience can make them ill-equipped to support the student during their placement.<sup>210</sup> There are situations where resource limitations or innate bigotry reduces the support offered by placement officers, industry partners and workers, and customers in the industry partner.<sup>211</sup> If a student is unable to complete a placement, or completes it with poor reviews, it can prevent the student from transitioning to a professional and may require them to retrain or find work as a non-professional.

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barriers to access in the past. See Erin Grewe, *Justice May Be Blind, but there is no Justice for the Visually Disabled: A Guide to the Administration of a Format-Neutral Bar Examination*, 21 TEMP. POL. & CIV. RTS. L. REV. 543, 550-51 (2012); Denise Riebe, *A Bar Review for Law Schools Getting Students on Board to Pass Their Bar Exams*, 45 BRANDEIS L.J. 269 (2007).

207 David K. Morris & Patricia A. Turnbull, *Clinical Experiences of Students with Dyslexia*, 54 J. ADVANCED NURSING 238 (2006); David K. Morris & Patricia A. Turnbull, *The Disclosure of Dyslexia in Clinical Practice: Experiences of Student Nurses in the United Kingdom*, 27 NURSE EDUC. TODAY 35 (2007); Jo Sanderson-Mann & Fiona McCandless, *Understanding Dyslexia and Nurse Education in the Clinical Setting*, 6 NURSE EDUC. IN PRACTICE 127 (2006).

208 Frances Howlin et al., *Development and Implementation of a Clinical Needs Assessment to Support Nursing and Midwifery Students with a Disability in Clinical Practice: Part 1*, 14 NURSE EDUC. IN PRACTICE 557, 558-62 (2014).

209 Sheila Blankfield, *Thick, Problematic and Costly? The Dyslexic Student on Work Placement*, SKILL J. 23 (2001).

210 *Id.*

211 See JANE WRAY ET AL., RESEARCH INTO ASSESSMENTS AND DECISIONS RELATING TO 'FITNESS' IN TRAINING, QUALIFYING AND WORKING WITHIN TEACHING, NURSING AND SOCIAL WORK (2007).



#### IV. Examining Practices from Australian Universities

Leading Australian universities are promulgating and lodging Disability Action Plans (DAPs) as a means of promoting disability inclusivity and ensuring their CRPD Article 24 compliance.<sup>212</sup> Some of these universities are also, with varied success, enhancing the disability voice in their communities and creating a culture of inclusion.

##### A. Disability Action Plans

The 1992 Australian *Disability Discrimination Act* creates a voluntary scheme, through which duty holders may elect to submit a DAP to the Australian Human Rights Commission (AHRC).<sup>213</sup> The AHRC in turn publishes these DAPs on their website.<sup>214</sup> Most Australian governmental entities have adopted policies requiring the drafting and lodging of DAPs as part of the state's commitment to promoting disability inclusion across the public sector.<sup>215</sup> At a minimum, DAPs must include the devising of policies and programs to promote disability inclusion and the communication, implementation, and review of those initiatives. Additionally, DAPs should identify who, in a given organization, is charged with carrying out the DAP.<sup>216</sup>

Within the Australian university sector, DAPs are high level strategic documents and are approved by vice chancellors.<sup>217</sup> They thus reflect the intention of these universities to actively embrace disability as a form of diversity and to enable students, academic and support staff, and the wider communities they serve to have the opportunity to contribute to and benefit from university life.<sup>218</sup> The

212 For example, The University of Queensland Disability Action Plan explains that “the University has a positive-solution-based-focus in achieving equality of outcomes as defined by the United Nations Convention on the Rights of Persons with Disabilities.” UNIV. OF QUEENSL., *DISABILITY ACTION PLAN 2016-2018* 15 (2017), <https://www.uq.edu.au/equity//filething/get/823/10042017-Disability%20Action%20Plan%202016-2018.pdf>.

213 *Disability Discrimination Act 1992* (Cth) pt 3 (Austl.).

214 See *Register of Disability Discrimination Act Action Plans*, AUSTRALIAN HUMAN RIGHTS COMM'N, [http://www.humanrights.gov.au/disability\\_rights/action\\_plans/register.html](http://www.humanrights.gov.au/disability_rights/action_plans/register.html) (last visited Jan. 8, 2017).

215 See NEIL REES ET AL., *AUSTRALIAN ANTI-DISCRIMINATION LAW* ch. 5.4 (2d ed. 2014).

216 *Disability Discrimination Act 1992* (Cth) p 3 s 61 (Austl.).

217 See, e.g., UNIV. OF QUEENSL., *DISABILITY ACTION PLAN 2016-2018* (2017), <https://www.uq.edu.au/equity//filething/get/823/10042017-Disability%20Action%20Plan%202016-2018.pdf>.

218 See *Disability Discrimination Act Action Plans: A Guide for the Tertiary Education*

implementation and success of DAPs are generally monitored and evaluated at the highest level of university governance.<sup>219</sup> The leading group of universities in Australia, called the Group of 8 (GO8),<sup>220</sup> has recognized the importance and value of DAPs, and six of the GO8 universities have current DAPs lodged with the AHRC.<sup>221</sup> DAPs previously lodged by the Australian National University and Monash University are out-of-date<sup>222</sup> and seemingly without plan for revision. Hence, even within a small, sophisticated, and well-resourced entity such as the GO8, practices vary regarding compliance.<sup>223</sup>

To illustrate this divergence: each of the current GO8 DAPs reflect the importance of the educator-student relationship, which, as regulated by the National Disability Education Standards, requires significant measures from universities.<sup>224</sup> Yet, they differ as to their scope. The University of New South Wales DAP refers to some extracurricular activities, but only ones organized on campus as part of university life.<sup>225</sup> The University of Melbourne's DAP goes further and supports students engaging in "co-curricular activities," meaning

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Sector, AUSTL. HUMAN RIGHTS COMM'N, <https://www.humanrights.gov.au/disability-discrimination-act-action-plans-guide-tertiary-education-sector> (last visited Jan. 8, 2017).

219 Thus, the AHRC advises that the ultimate responsibility for implementing DAPs in the university sector "lies with the University Council through the Vice-Chancellor." *Id.* at app. 2.

220 The GO8 is comprised of The University of Melbourne, The Australian National University, The University of Sydney, The University of Queensland, The University of Western Australia, The University of Adelaide, Monash University, and UNSW Sydney. *See About, GROUP OF EIGHT AUSTL.*, <https://go8.edu.au/page/about> (last visited Dec. 29, 2017).

221 UNIV. OF ADELAIDE, DISABILITY ACTION PLAN 2014-2019 (2017), [http://www.humanrights.gov.au/sites/default/files/1972-5%20Disability%20Action%20Plan\\_March%202017%20update.pdf](http://www.humanrights.gov.au/sites/default/files/1972-5%20Disability%20Action%20Plan_March%202017%20update.pdf); UNIV. OF MELBOURNE, DISABILITY ACTION PLAN 2014-2018 (2014), [https://services.unimelb.edu.au/\\_\\_data/assets/pdf\\_file/0004/954067/Disability\\_Action\\_Plan\\_2014-2018.pdf](https://services.unimelb.edu.au/__data/assets/pdf_file/0004/954067/Disability_Action_Plan_2014-2018.pdf); UNIV. OF N.S.W., DISABILITY ACTION PLAN 2014-2018 (2014), <http://www.studentlifelifelearning.unsw.edu.au/sites/default/files/uploads/UNSWDisabilityActionPlan.pdf>; UNIV. OF QUEENSL., *supra* note 217; UNIV. OF SYDNEY, DISABILITY ACTION PLAN 2013-18 (2013), <https://sydney.edu.au/about-us/vision-and-values/diversity/disability-action-plan.html>; *University Policy on: Disability and Medical Conditions*, UNIV. OF W. AUSTL. (Dec. 6, 2015), <http://www.student.uwa.edu.au/experience/health/uniaccess/policy/disability>; *see also* AUSTL. HUMAN RIGHTS COMM'N, *supra* note 214.

222 AUSTL. HUMAN RIGHTS COMM'N, *supra* note 214.

223 As an aside, the experiences of the authors is that the same may be said to occur *within* universities, for instance, as between schools.

224 REES ET AL., *supra* note 215, at ch. 7.

225 UNIV. OF N.S.W., *supra* note 221, at 3.

extracurricular activities that support the student's development but may not be required as part of a course.<sup>226</sup> Similarly, the University of Western Australia DAP extends its scope to student recreational activities.<sup>227</sup> The fact that other university DAPs do not refer to "co-curricular activities" may not mean that policies and practices in these universities do not extend support to such activities.

A significant good practice example within the GO8 is the University of Adelaide's DAP, which mandates that support to potential and current students extend to: admission and enrollment; academic activities; curriculum development, assessment, and certification requirements; physical access to buildings and facilities; information access; and the creation of a safe learning environment.<sup>228</sup> Another good practice example is the University of Queensland's DAP, which requires the university to annually assess the retention rate among students who identify as having a disability, and to evaluate the effectiveness of the support measures in place for students with disabilities.<sup>229</sup>

### **B. Enhancing the Disability Voice**

The current GO8 DAPs each include the formation and appointment of a committee to implement and/or monitor their respective university's policies and practices.<sup>230</sup> This measure is clearly a positive one, yet the representation of persons with disabilities on those committees varies. Persons with disabilities are not expressly provided a voice in the DAP implementation or monitoring groups in the University of Adelaide, University of Melbourne or the University of New South Wales Plans.<sup>231</sup> By contrast, the University of Sydney Disability Action Plan Consultative Committee includes staff and student representatives—however, there is no guarantee that these representatives are persons with disabilities.<sup>232</sup> The University of Western Australia goes somewhat further and provides that the "Inclusion and Diversity Committee . . . may co-opt experts in the area, practitioners, and disability academics and advocates to assist with planning and implementation."<sup>233</sup> The

226 UNIV. OF MELBOURNE, *supra* note 221.

227 UNIV. OF W. AUSTL., *supra* note 221.

228 UNIV. OF ADELAIDE, *supra* note 221.

229 UNIV. OF QUEENSL., *supra* note 217, at 10.

230 UNIV. OF ADELAIDE, *supra* note 221, at 8.

231 UNIV. OF ADELAIDE, *supra* note 221; UNIV. OF MELBOURNE, *supra* note 221; UNIV. OF N.S.W., *supra* note 221.

232 UNIV. OF SYDNEY, *supra* note 221.

233 UNIV. OF W. AUSTL., *supra* note 221.

University of Queensland's DAP involves the formation of staff and student disability consultative groups/communities of practice that include staff and students with disabilities.<sup>234</sup> This has resulted in the formation of a committee called the Staff and Student Disability Consultative Group, which is answerable to the Pro-Vice-Chancellor (Office of the Provost) and the University Senate Committee for Equity, Diversity and the Status of Women.<sup>235</sup>

A key fundamental principle in the new disability human rights paradigm<sup>236</sup> is that persons with disabilities should have a voice in the conceptualization, formation, implementation, and reviewing of policies and practices that impact upon ability equality.<sup>237</sup> This "participatory justice dynamic" underscores key provisions of the CRPD<sup>238</sup> and, as indicated above, is rightfully reflected in some of the current GO8 DAPs. When DAPs do not expressly provide for the inclusion of persons with disabilities, universities should revise them accordingly and consider students and staff with disabilities as essential to reviewing and implementing their respective DAPs. The success of The University of Queensland Staff and Student Disability Consultative Group illustrates that there is an abundance of staff and students with disabilities who have the capabilities and capacity to become involved,<sup>239</sup> and that such participation helps build capacity within these groups, while providing a strong platform for creating a disability inclusive voice.<sup>240</sup>

### C. *Creating a Culture of Inclusion*

Many universities across the globe are seeking to promote

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234 UNIV. OF QUEENSL., *supra* note 217, at 6.

235 For the terms of reference of this group, see *Staff and Student Disability Consultive Group* (Nov. 4, 2016), <https://staff.uq.edu.au/files/227/disability-consultative-group-terms-of-reference.pdf>. The Committee is chaired by Dr. Paul Harpur.

236 Stein, *supra* note 25, at 84.

237 Paul Harpur, *Nothing About Us Without Us: The UN Convention on the Rights of Persons with Disabilities*, in OXFORD RESEARCH ENCYCLOPEDIA OF POLITICS 1 (Anika Leithner & Kyle Libby eds., 2017).

238 Stein & Lord, *supra* note 26, at 37.

239 *Staff and Student Disability Consultative Group*, U. OF QUEENSL., <https://staff.uq.edu.au/information-and-services/human-resources/diversity/commitment/disability-consultative-group> (last visited Apr. 19, 2018).

240 See Philip Vickerman & Milly Blundell, *Hearing the Voices of Disabled Students in Higher Education*, 25 DISABILITY & SOC. 21 (2010) (identifying five key barriers to educational equality being: "pre-course induction support, commitment by [universities] . . . to facilitating barrier free curricula, consultation with disabled students, institutional commitment to develop support services and embedding of personal development planning.").

disability inclusive higher education by adopting innovative programming<sup>241</sup> and, as noted throughout this article, best practice examples exist of universities devising and implementing strategic initiatives towards that end.<sup>242</sup> These examples are mainly positive. Nevertheless, students with disabilities in higher education experience substantial and continuing stigma and prejudice both in terms of systemic institutional arrangements, as well as in their daily interactions with fellow university community members.<sup>243</sup> In addition to certain impairment types attracting greater levels of stigma,<sup>244</sup> students do not experience their disability in isolation from other sites of oppression, such as the intersecting attributes of disability and race,<sup>245</sup> or disability and sexuality,<sup>246</sup> disability and domestic violence.<sup>247</sup>

Collectively, culture change remains a great and universal

241 See Dalia Sachs & Naomi Schreuer, *Inclusion of Students with Disabilities in Higher Education: Performance and Participation in Student's Experiences*, 31 *DISABILITY STUD. Q.* (2011), <http://dsq-sds.org/article/view/1593/1561>; Madison Rexroat, *Intellectually Disabled Students Gaining More Opportunities in Higher Education*, *THE KY. KERNEL* (Jun. 6, 2017), [http://www.kykernel.com/kernel\\_plus/intellectually-disabled-students-gaining-more-opportunities-in-higher-education/article\\_d32807c0-4a59-11e7-a677-f372f67f0e18.html](http://www.kykernel.com/kernel_plus/intellectually-disabled-students-gaining-more-opportunities-in-higher-education/article_d32807c0-4a59-11e7-a677-f372f67f0e18.html).

242 Notable in that regard is the recent publication by the National Center for College Students with Disabilities, which recommends detailed institutional changes. See Wendy S. Harbour & Daniel Greenberg, *NCCSD Research Brief: Campus Climate and Students with Disabilities* (2017), <http://www.nccsdonline.org/research-briefs.html>.

243 See, e.g., THOMAS HEHIR & LAURA A. SCHIFTER, *HOW DID YOU GET HERE?: STUDENTS WITH DISABILITIES AND THEIR JOURNEYS TO HARVARD* 8, 168, 203–07, 209–10 (Harv. Ed. Press 2015).

244 Paul Harpur et al., *Socially Constructed Hierarchies of Impairments at Work: Example of the Australian and Irish Workers' Access to Compensation for Injuries*, 27 *J. OCCUPATIONAL REHAB.* 507 (2017) (arguing that “[v]alue judgments in workplace culture and local law mean that the extent of disadvantage experienced by workers with disabilities additionally will depend upon the type of impairment they have. Rather than focusing upon the extent and severity of the impairment and how society turns an impairment into a recognized disability, [these authors] . . . critically analyse the social hierarchy of physical versus mental impairment.”).

245 Robert Mitchell, *Gay Marine Helps Change History*, *HARVARD GAZETTE* (Apr. 7, 2017), <https://news.harvard.edu/gazette/story/2017/04/eric-alva-shares-story-of-being-gay-a-marine-and-changing-history/>.

246 See, e.g., Ryan A. Miller, Richmond D. Wynn & Kristine W. Webb, *Queering Disability in Higher Education: Views from the Intersections*, in *DISABILITY AS DIVERSITY*, *supra* note 50, at 31–44.

247 Paul Harpur & Heather Douglas, *Disability and Domestic Violence: Protecting Survivors' Human Rights*, 23 *GRIFFITH L. REV.* 405 (2014).



challenge for universities,<sup>248</sup> even among those leading examples that purport to be CRPD (or ADA) compliant.<sup>249</sup> Thus, an elevator breaking down can be a human rights issue for those who cannot move between floors using steps,<sup>250</sup> as well as inaccessible building renovations that require the relocation of students with mobility limitations.<sup>251</sup> Perhaps even more pervasive are the frequently hostile environments created by fellow university students, staff and/or educators,<sup>252</sup> including those who characterize in-class or examination accommodations as privileging and advantageous,<sup>253</sup>

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248 It is difficult to otherwise explain why nearly two centuries elapsed between the only two deaf-blind students to have attended any program within Harvard University. Compare *Helen Keller Biography*, AM. FOUND. FOR THE BLIND <http://www.afb.org/info/about-us/helen-keller/biography-and-chronology/biography/1235>, (last visited Jan. 8, 2017) (graduating from Radcliffe College in 1904, becoming the first deaf-blind person to earn a bachelor of arts), with Joseph Shapiro, *She Owes Her Activism to a Brave Mom, the ADA and Chocolate Cake*, NAT'L PUB. RADIO, <https://www.npr.org/sections/goatsandsoda/2015/07/31/428075935/she-owes-her-activism-to-a-brave-mom-the-ada-and-chocolate-cake> (last visited Jan. 8, 2017), and Frank Stasio & Nicole Campbell, *First Deaf-Blind Student at Harvard Law Pursues Dreams*, N.C. PUB. RADIO (Nov. 1, 2013), <http://wunc.org/post/first-deaf-blind-student-harvard-law-pursues-dreams#stream/0> (recounting the life story of Haben Girma, who graduated from Harvard Law School in 2013 as its first deaf-blind student).

249 See Piro, *supra* note 163; Ausseil et al., *supra* note 163.

250 See Baldelomar, *supra* note 162 (recounting the exclusion and subordination of a University of Kansas graduate student with a mobility impairment).

251 See Ashley Wong, *Newly Renovated Wheeler Hall Inaccessible to Students with Disabilities*, THE DAILY CALIFORNIAN (Aug. 28, 2017), <http://www.dailycal.org/2017/08/28/new-wheeler-hall-elevator-creates-difficulty-for-students-with-disabilities/>. We note that this deplorable incident occurred at the University of California, Berkeley, the birthplace of the modern American disability rights movement. *Id.*

252 See THOMAS HEHIR & LAURA A. SCHIFTER, *HOW DID YOU GET HERE?: STUDENTS WITH DISABILITIES AND THEIR JOURNEYS TO HARVARD* 8 (Harv. Ed. Press 2015).

253 See, e.g., Amanda M. Foster, *Reasonable Accommodations on the Bar Exam: Leveling the Playing Field or Providing an Unfair Advantage?*, 48 VAL. U. L. REV. 661 (2014) (“If you ask law students what they think about examination accommodations provided to students with disabilities, including learning disabilities, most students will tell you that it is unfair that some students get more time to take an examination.”); Maya Venters, *Equality Is Not Equity: The Argument For Academic Accommodations*, ONT. UNDERGRADUATE STUDENT ALL. (Aug. 30, 2017), [http://www.ousa.ca/blog\\_equality\\_is\\_not\\_equity](http://www.ousa.ca/blog_equality_is_not_equity) (critiquing the statements of a Professor of Law at Queen’s University, who argued that students were taking advantage of accommodations to “get ahead of their peers”). These arguments likewise form the basis of an academic critique of accommodations provided under the Individuals with Disabilities Education

rather than as levelling an uneven playing field.<sup>254</sup> To put this issue in graphic relief, a recent survey of 13,844 students in higher education found that 22% of students with disabilities had experienced offensive verbal comments relating to their disability status.<sup>255</sup>

Many students with disabilities are exceptional students who achieve at the top of their class.<sup>256</sup> They are positive and focused on the end goal of becoming graduates and leaders of industry, the academy, and the community.<sup>257</sup> In doing so, students with disabilities overcome all the regular challenges faced by their peers, in addition to other, gratuitously created, barriers arising through outmoded cultural mores.<sup>258</sup> Consequently, students with disabilities in higher education often achieve despite their university's inactions<sup>259</sup> rather

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Act. See MARK KELMAN & GILLIAN LESTER, *JUMPING THE QUEUE: AN INQUIRY INTO THE LEGAL TREATMENT OF STUDENTS WITH LEARNING DISABILITIES* (1998).

254 *But see* Stein, *supra* note 85.

255 K. C. Aquino et al., “Does Disability Matter?” *Students’ Satisfaction with College Experiences*, in *DISABILITY AS DIVERSITY*, *supra* note 50, at 51–55.

256 There are numerous examples of such students, but we note that Doaa Abu Elyounes, a blind, Israeli-Arab LLM Harvard Law School graduate (now SJD candidate) and finalist for the Gary Bellow Public Service Award, illustrates this point. See Liz Mineo, *Unlimited Resolve*, *HARV. GAZETTE* (May 26, 2016), <https://news.harvard.edu/gazette/story/2016/05/unlimited-resolve/>; *Doaa Abu Elyounes*, *HARV. L. SCH.* (March 23, 2017), <http://hls.harvard.edu/dept/graduate-program/doaa-abu-elyounes/>.

257 See, e.g., Elizabeth Ramos & Megan Savage, *Students with Disabilities Highlight Resiliency, Optimism*, *THE LANTERN* (Apr. 22, 2009), <https://www.thelantern.com/2009/04/students-with-disabilities-highlight-resiliency-optimism/>. See also ISAAC LIDSKY, *EYES WIDE OPEN: OVERCOMING OBSTACLES AND RECOGNIZING OPPORTUNITIES IN A WORLD THAT CAN’T SEE CLEARLY* (2017).

258 See, e.g., Sarah Chaney, “*Breaking Bad*” Actor RJ Mitte Visited UNC, Shared His Experiences with Disability, *THE DAILY TAR HEEL* (Apr. 3, 2014), <http://www.dailytarheel.com/article/2014/04/breaking-bad-actor-rj-mitte-visited-unc-shared-his-experiences-with-disability> (“I overcame it with lots of exercises — lots of painful, painful exercises.”); Kristen Larson, *Fumagalli Doesn’t Consider Missing Finger a Disability, Rather an Opportunity for Growth*, *THE BADGER HERALD* (Nov. 7, 2017), <https://badgerherald.com/sports/2017/11/07/fumagalli-doesnt-consider-missing-finger-a-disability-rather-an-opportunity-for-growth/> (“According to Fumagalli, some have tried to make him seem heroic for his missing appendage, but that is not how he likes to look at it.”); Gabriella Santoliquito, “*The Facts of Life*” Star Geri Jewell Discusses Disabilities, Acting Career, *DAILY COLLEGIAN* (Oct. 17, 2014), [http://www.collegian.psu.edu/news/campus/article\\_633caaa2-5591-11e4-a559-001a4bcf6878.html](http://www.collegian.psu.edu/news/campus/article_633caaa2-5591-11e4-a559-001a4bcf6878.html) (stating that she was “wired” to fight for everything and highlight her abilities).

259 Editorial Board, *Administrators Should Look Out For Ableism, Prioritize Students*



than because of their university's actions.

## V. Conclusion

The CRPD establishes a framework through which to transform societies from a state of disability exclusion to one of disability inclusion. This article examined that directive in the context of higher education. Section II described how CRPD Article 24 ensures that students with disabilities have equal access to higher education for the first time in international law. Section III set forth the basic obligations incumbent upon States Parties' universities to achieve disability-inclusive higher education. Lastly, Section IV provided a case study of Australian universities with practical examples of how those institutions of higher learning honor, at times fall short, and at times exceed their CRPD obligations.

Universities are well situated to help transform power imbalances for persons with disabilities in their respective societies. Universities are where children become young adults—in terms of reaching the age of majority—and in the more essential sense of gaining independence, evolving their identities, undertaking new experiences, and developing social and intimate relationships in ways that influence the rest of their lives. Likewise, universities are where students learn skills for becoming young professionals and creating social networks and capital that they can utilize in their careers. Put another way, because professional and intimate relationships often start at university, excluding students with disabilities from such opportunities damages them professionally and as social beings.

Although university qualifications do not guarantee success, and are not always required for success, most professions require such qualifications for entry. Consequently, the capacity to access disability inclusive university education can be the difference between people with disabilities becoming accountants, lawyers or physicians, or becoming cleaners, laborers, or working in a sheltered workshop. Fully participating in the university experience enables students with disabilities to access life-changing and career-developing opportunities that the wider student cohort accesses as an expected and “normal” matter of passage.

Universities can and should play a key role in advancing their respective State's rights-based agenda as mandated by the CRPD. In many ways, universities are uniquely situated to become change

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*with Disabilities*, THE DAILY BRUIN (Jul. 30, 2017), <http://dailybruin.com/2017/07/30/editorial-administrators-should-look-out-for-ableism-prioritize-students-with-disabilities/>.

agents and use their privileged position to transform themselves, the students they mold, the staff they employ, and the wider community to evolve from tolerating limited difference to accepting diversity, and to enable all persons with disabilities to move from welfare and charity to economic independence and work.

One dramatic example of how universities can enable students with disabilities is by funding research to understand the barriers to disability inclusion and how these barriers can be remedied. Unfortunately, there remains a paucity of information on the extent to which different hardware and software products and settings are disability inclusive. Thus, it may seem hard to ensure disability inclusion. Without adequate information, creating a disability inclusive law office, for example, can feel more complex than it is in reality. What computers, web design, software, scanners, photocopiers, telephones and the like are able to be used by people with disabilities? What requires expensive or inexpensive modifications to become usable? What cannot be modified to become accessible? Product designers do not provide this information in most situations, and so to the uninitiated inclusion might feel daunting. To this end, university researchers occupy a powerful and privileged space from which to help develop best practices and reduce the complexities confronting other decision makers who are willing to make a space disability inclusive but are unsure how to do so.

## A Call for an End to Violence Against Women and Girls with Disabilities under International and Regional Human Rights Law

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## I. Introduction

In 2012, Professor Hope Lewis and Stephanie Ortoleva published a Northeastern University School of Law research paper entitled, *Forgotten Sisters – A Report on Violence Against Women with Disabilities: A Review of its Nature, Scope, Causes and Consequences*.<sup>1</sup> This paper was the first comprehensive, country-by-country analysis of the scope of the problem of violence against women and girls with disabilities throughout the world. Its aim was straightforward—to raise awareness about the lack of international and domestic legal protections for women and girls with disabilities who experience violence in most, if not all, countries of the world. As Lewis and Ortoleva observed, “women with disabilities constitute a significant portion of the global population and . . . the pervasive violence against women with disabilities must be addressed.”<sup>2</sup>

In 2000, the United Nations General Assembly proclaimed that “girls and women of all ages with any form of disability are generally among the more vulnerable and marginalized of society.”<sup>3</sup> Since then, the issue of violence against women and girls with disabilities has gained greater attention on the international stage. In 2011, the United Nations Human Rights Council requested the Office of the High Commissioner for Human Rights to prepare a study on violence and disability, recognizing that disability can be both a cause and consequence of violence against women with disabilities.<sup>4</sup> Activists and policymakers began to call for applying the protections of the Convention on the Elimination of Discrimination

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1 STEPHANIE ORTOLEVA & HOPE LEWIS, NORTHEASTERN PUBLIC LAW & THEORY FACULTY RESEARCH PAPER SERIES NO. 104-2012, *FORGOTTEN SISTERS – A REPORT ON VIOLENCE AGAINST WOMEN WITH DISABILITIES: AN OVERVIEW OF ITS NATURE, SCOPE, CAUSES AND CONSEQUENCES* (2012).

2 *Id.* at 13.

3 G.A. Res. S-23/3, annex, ¶ 63, Further Actions and Initiatives to Implement the Beijing Declaration and Platform for Action (Nov. 16, 2000).

4 See Human Rights Council Res. 17/11, U.N. Doc. A/HRC/17/L.6 (June 10, 2011). The Resolution states, in pertinent part: “11. Invites the Office of the High Commissioner to prepare a thematic analytical study on the issue of violence against women and girls and disability, in consultation with the Special Rapporteur on violence against women, its causes and consequences, the Special Rapporteur on disability of the Commission for Social Development of the Economic and Social Council, other relevant special procedure mandate holders, States, United Nations entities, regional organizations, civil society organizations and other relevant stakeholders, and to report to the Human Rights Council at its twentieth session.”

against Women<sup>5</sup> and the Convention on the Rights of the Child<sup>6</sup> to women and girls with disabilities, respectively.<sup>7</sup> Moreover, in 2006, the United Nations adopted the Convention on the Rights of Persons with Disabilities (CRPD), which is the first international treaty to specifically protect the rights of all people with disabilities, including women and girls with disabilities.<sup>8</sup> Among other provisions, the CRPD requires States Parties to develop and implement programs designed to stop violence, abuse, and exploitation of women and girls with disabilities, including involuntary sterilization and forced abortion.<sup>9</sup>

Despite the widespread adoption of the CRPD as well as other international and regional human rights treaties and domestic laws, violence, abuse, and exploitation of women and girls with disabilities continues throughout the world.<sup>10</sup> Moreover, most women and girls who experience violence remain unable to access a system of justice that should provide them with protection from violence as well as redress and reparations.<sup>11</sup> Even in those countries where the domestic laws appear to ensure access to justice, formidable barriers exist which prevent many women and girls with disabilities who experience violence from enforcing their rights under law.<sup>12</sup>

This article analyzes the role of international and regional human rights law in protecting the rights of women and girls with disabilities to be free from violence and to access justice. Section II of the article presents an overview of the problem of violence against women with disabilities, followed by Section III which identifies and discusses the many legal, physical, and attitudinal barriers that prevent women and girls with disabilities from exercising their right to access the judicial system. Section IV discusses the Convention on the Elimination of Discrimination Against Women

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5 G.A. Res. 34/180, Convention on the Elimination of All Forms of Discrimination Against Women (Dec. 18, 1979) [hereinafter CEDAW].

6 G.A. Res. 44/25, Convention on the Rights of the Child (Nov. 20, 1989) [hereinafter CRC].

7 CRPD Comm., *General Comment No. 3: Article 6: Women and Girls with Disabilities*, ¶ 6, U.N. Doc. CRPD/C/GC/3 (Nov. 25, 2016).

8 G.A. Res. 61/106, Convention on the Rights of Persons with Disabilities (Dec. 13, 2006) [hereinafter CRPD]. See ARLENE S. KANTER, *THE DEVELOPMENT OF DISABILITY RIGHTS UNDER INTERNATIONAL LAW: FROM CHARITY TO HUMAN RIGHTS* 31–35 (2015).

9 CRPD, *supra* note 8, arts. 6, 7, 12, 15, 16, 17, 23, & 25.

10 *See infra* Section II.

11 *See infra* Section III.

12 *See infra* Section VI.



(CEDAW), the Convention on the Rights of the Child (CRC), and the Convention on the Rights of Persons with Disabilities (CRPD), which provide some protections for women and girls with disabilities who experience violence. Part V discusses related regional legal protections for women and girls with disabilities within the regional human rights systems of the Americas, Africa, and Europe. Part VI of the article discusses Peru as an example of a country that has ratified all relevant international and regional treaties on the rights of women with disabilities, and has enacted new domestic laws and policies to address discrimination and violence against women with disabilities. However, even Peru continues to apply discriminatory laws and policies that deprive women with disabilities access to justice. As the Peruvian example illustrates, so long as domestic laws deprive women of their legal capacity, the vision and protections for them under domestic as well as international and regional human rights treaties will not be realized.<sup>13</sup> Part VII of the article, therefore, provides recommendations that should be implemented to prevent violence against women and girls with disabilities and ensure their access to justice. The article concludes with a call for greater international, regional and country-specific laws, policies, and advocacy to prevent violence against women and girls with disabilities and ensure their access to justice.

## **II. The Problem of Violence Against Women and Girls with Disabilities and Barriers to its Elimination**

### ***A. Overview of the Problem of Violence Against Women and Girls with Disabilities***

Today, at least half of the billion people with disabilities in the world are women and girls, the majority of whom live in developing countries.<sup>14</sup> Although millions of women and girls throughout the world experience violence, those with disabilities experience more

13 *General Comment No. 3: Article 6: Women and Girls with Disabilities*, *supra* note 7, ¶ 10. See also CRPD Comm., *Concluding Observations on the Initial Report of Belgium*, ¶¶ 23, 30, U.N. Doc. CRPD/C/BEL/CO/1 (Oct. 28, 2014) [hereinafter *Concluding Observations Belgium*]. The Committee is concerned about the lack of protection for women, children, and girls with disabilities against violence and abuse. It is also concerned about the absence of protocols to register, monitor and track the conditions in institutions that care for persons with disabilities, particularly those that care for older persons with disabilities.

14 WORLD HEALTH ORG. & WORLD BANK, *WORLD REPORT ON DISABILITY*, xi, 10, 27, 28, 30 (2011).

violence, more often, in additional settings, in different forms, and by different perpetrators than those without disabilities.<sup>15</sup> The United Nations has recognized that women with disabilities are “among the more vulnerable and marginalized [group of people] of society.”<sup>16</sup>

In 2012, the Special Rapporteur on Violence Against Women recognized that women with disabilities face a greater risk of violence, exploitation and abuse compared to nondisabled women.<sup>17</sup> The Special Rapporteur found that women with disabilities are more likely to experience abuse over a longer period of time than do women without disabilities.<sup>18</sup> Indeed, research has shown that women and girls with disabilities are particularly vulnerable to violence,<sup>19</sup> abuse,<sup>20</sup> as well as infringement of their reproductive rights, including involuntary sterilization and forced abortion.<sup>21</sup>

Similarly, the USAID has found that women with disabilities throughout the world are two to three times more likely to suffer physical and sexual abuse than women without disabilities.<sup>22</sup> They

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15 DISABLED WOMEN'S NETWORK OF CAN., FACTSHEET: WOMEN WITH DISABILITIES AND VIOLENCE 1 (2014), <http://www.dawncanada.net/main/wp-content/uploads/2014/03/English-Violence-January-2014.pdf>.

16 G.A. Res. S-23/3, *supra* note 3.

17 Rashida Manjoo (Special Rapporteur on Violence Against Women, its Causes and Consequences), *Report of the Special Rapporteur on Violence Against Women, its Causes and Consequences*, ¶¶ 13, 31, U.N. Doc. A/67/227 (Aug. 3, 2012).

18 *Id.*

19 *General Comment No. 3: Article 6: Women and Girls with Disabilities*, *supra* note 7, ¶ 10; *see also Concluding Observations Belgium*, *supra* note 13; CRPD Comm., *Concluding Observations on the Initial Report of Australia*, ¶ 16, U.N. Doc. CRPD/C/AUS/CO/1 (Sept. 13, 2013) [hereinafter *Concluding Observations Australia*]; CRPD Comm., *Concluding Observations on the Initial Report of China*, ¶¶ 57, 65, 90, U.N. Doc. CRPD/C/CHN/CO/1 (Oct. 15, 2012) [hereinafter *Concluding Observations China*].

20 CRPD Comm., *Concluding Observations on the Initial Report of El Salvador*, ¶ 37, U.N. Doc. CRPD/C/SLV/CO/1 (Sept. 13, 2013) [hereinafter *Concluding Observations El Salvador*]; CRPD Comm., *Concluding Observations on the Initial Report of Czech Republic*, ¶ 34, U.N. Doc. CRPD/C/CZE/CO/1 (May 15, 2015) [hereinafter *Concluding Observations Czech Republic*].

21 CRPD Comm., *Concluding Observations on the Initial Report of Mauritius*, ¶ 29, U.N. Doc. CRPD/C/MUS/CO/1 (Sept. 30, 2015) [hereinafter *Concluding Observations Mauritius*]; *Concluding Observations on the Initial Report of New Zealand*, ¶ 37, U.N. Doc. CRPD/C/NZL/1 (Oct. 1, 2013) [hereinafter *Concluding Observations New Zealand*].

22 U.S. AGENCY FOR INT'L DEV., UNITED STATES STRATEGY TO PREVENT AND RESPOND TO GENDER-BASED VIOLENCE GLOBALLY 7 (Aug. 10, 2012), <https://reliefweb.int/report/world/united-states-strategy-prevent->

are also two to three times more likely to experience physical violence throughout their lives,<sup>23</sup> and four times more likely to experience sexual violence, than women without disabilities.<sup>24</sup> Women with disabilities also report higher incidents of disability than men in most Organisation for Economic Co-operation and Development (OECD) countries.<sup>25</sup>

Violence against women and girls with disabilities can take different forms than violence against women and girls without disabilities, especially with respect to neglect, physical abuse, sexual abuse, psychological abuse, financial exploitation and forced social isolation.<sup>26</sup> Women with disabilities also experience a wider range of emotional, physical and sexual abuse by caretakers.<sup>27</sup> Abuse of women and girls with disabilities can occur as a result of physical assault, a caretaker's or family member's deliberate withholding of lifesaving equipment and devices, such as wheelchairs, canes, respirators, or other assistive devices, or denying a deaf or blind woman or girl access to accommodations, such as braille, sign language interpreting, or information in other accessible formats.<sup>28</sup> Denial of such equipment and information can be the difference between life and death for some women and girls with disabilities.

Like violence against women and girls without disabilities, violence against women and girls with disabilities can be perpetrated by intimate partners and family members in their homes or by neighbors and strangers outside of their homes. As discussed in the following section, women and girls with disabilities also experience violence, abuse, and exploitation by an additional category of potential perpetrators: caregivers, personal attendants, and guardians—individuals who are charged with their care. Women

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and-respond-gender-based-violence-globally (citing U.K. DEP'T FOR INT'L DEV., *DISABILITY, POVERTY AND DEVELOPMENT* (2000)).

23 *Id.*

24 Annual Rep. of the Office of the U.N. High Comm'r for Human Rights, Thematic Study on the Issue of Violence Against Women and Girls and Disability, ¶ 21, U.N. Doc. A/HRC/20/5 (Mar. 30, 2012) [hereinafter OHCHR Annual Report] (citing European Parliament, *Report on the Situation of Minority Women in the European Union*, 13, EU Doc 2006/2277(INI) (Apr. 26, 2007)).

25 U.N. Div. for Soc. Policy & Dev. Disabilities, *Factsheet on Persons with Disabilities*, DIVISION FOR SOCIAL POLICY AND DEVELOPMENT DISABILITY, <https://www.un.org/development/desa/disabilities/resources/factsheet-on-persons-with-disabilities.html> (last visited Apr. 17, 2018).

26 ORTOLEVA & LEWIS, *supra* note 1, at 14, 16.

27 *Id.*

28 *See id.* 1, at 39.

and girls with disabilities also may experience violence by the State itself from its failure to protect them from neglect and abuse in institutions, and by state-sponsored or approved forced treatment, including involuntary sterilization and forced abortion.<sup>29</sup>

### ***B. Violence Against Women and Girls with Disabilities at Home and in Institutions***

Violence against women and girls with and without disabilities can occur in their own homes, by their intimate partners or family members. And, like women and girls without disabilities, women and girls with disabilities may be reluctant to leave an abuser due to a relationship of dependence, fear of losing custody of their children, and/or having low self-esteem, which is a risk factor for domestic violence.<sup>30</sup> Such factors make it more difficult for all women who experience violence to break off the relationship with the perpetrator. However, women and girls with disabilities face additional risks as well.

Since women and girls with disabilities may be dependent on other people for their survival, they are at greater risk of violence, abuse, and exploitation by people charged with their care, such as caregivers, personal attendants, and legal guardians. Yet when the perpetrator is a caregiver, personal attendant, or guardian, the woman with a disability may be less likely to report such mistreatment for fear of losing the assistance on which her life, quite literally, depends.<sup>31</sup>

A small 2004 survey in Orissa, India found, for example, that virtually all women and girls with disabilities in the state were beaten at home; that 25% of women with intellectual disabilities were raped; and that 6% of women with disabilities were forcibly sterilized.<sup>32</sup>

In Kenya, too, a recent study of women with intellectual disabilities found that 57.4% of women and girls with intellectual disabilities who lived at home had been sexually assaulted “most of the time[,]”<sup>33</sup> and that 51% of the perpetrators were men “from the

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29 *Id.* at 41–46.

30 *Id.* at 12.

31 *General Comment No. 3: Article 6: Women and Girls with Disabilities*, *supra* note 7, ¶ 52.

32 U.N. Div. for Soc. Policy & Dev. Disabilities, *supra* note 25.

33 COAL. ON VIOLENCE AGAINST WOMEN & KENYA ASS'N OF THE INTELLECTUALLY HANDICAPPED, BASELINE SURVEY: THE KNOWLEDGE, AWARENESS, PRACTICE & PREVALENCE RATE OF GENDER BASED

neighborhood” who were known to the women.”<sup>34</sup> Moreover, at least 60.3% of the respondents who had been sexually abused reported that, at one time or another, they had been neglected by their own family members and lacked adequate community support.<sup>35</sup>

In addition, in traditional and patriarchal communities in which girls and young women are forced to marry at young ages to ensure their future security, young women and girls with disabilities are further stigmatized, as they are considered ineligible for marriage.<sup>36</sup> In fact, some families attempt to keep secret the disability of a daughter for fear that suitors will find her, as well as her siblings, unsuitable for marriage.<sup>37</sup> In other communities, women with disabilities are sought out for sex by men who mistakenly believe that having sex with them is an acceptable way to “cleanse” themselves from the HIV/AIDS virus.<sup>38</sup> The CRPD Committee has specifically condemned such practices as a violation of human rights law.<sup>39</sup>

In addition to violence in the home, women and girls with disabilities are particularly at risk of violence in institutions.<sup>40</sup>

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VIOLENCE AMONG ESPECIALLY SEXUAL VIOLENCE AMONG WOMEN & GIRLS WITH INTELLECTUAL DISABILITIES 10 (Coal. on Violence Against Women ed., 2013), <http://covaw.or.ke/wp-content/uploads/2014/01/Covaw-report-new-final-interactive.pdf>.

34 *Id.* at 11.

35 *Id.*

36 *General Comment No. 3: Article 6: Women and Girls with Disabilities*, *supra* note 7, ¶¶ 36–37; *see generally* ERA SHRESTHA ET AL., UNCOVERED REALITIES: EXPLORING EXPERIENCES OF CHILD MARRIAGE AMONG CHILDREN WITH DISABILITIES (Plan Int’l Nor. ed., 2017).

37 *See* Tony Emmett & Erna Alant, *Women and Disability: Exploring the Interface of Multiple Disadvantage*, 23 DEV. SOUTHERN AFR. 445, 455 (2006); William John Hanna et al., *Women with Disabilities: Two Handicaps Plus*, 6 DISABILITY, HANDICAP & SOC’Y 49, 52 (1991).

38 Nora E. Groce, *Rape of Individuals with Disability: AIDS and the Folk Belief of Virgin Cleansing*, 363 THE LANCET 1663, 1663–64 (2004).

39 *See, e.g.*, CRPD Comm., *Concluding Observations on the Initial Report of Kenya*, ¶¶ 33–34, U.N. Doc. CRPD/C/KEN/CO/1 (2015) [hereinafter *Concluding Observations Kenya*]; CRPD Comm., *Concluding Observations on the Initial Report of Gabon*, ¶¶ 40–41, U.N. Doc. CRPD/C/GAB/CO/1 (Oct. 2, 2015) [hereinafter *Concluding Observations Gabon*]; CRPD Comm., *Concluding Observations on the Initial Report of Uganda*, ¶¶ 34–35, U.N. Doc. CRPD/C/UGA/CO/1 (2016); CRPD Comm., *Concluding Observations on the Initial Report of Ethiopia*, ¶¶ 39–40, U.N. Doc. CRPD/C/ETH/CO/1 (2016).

40 *Cf.* LISA ADAMS, DISABILITY MONITOR INITIATIVE FOR SOUTH EAST EUROPE, HANDICAP INT’L REG’L OFFICE FOR S.E. EUR., THE RIGHT TO LIVE IN THE COMMUNITY: MAKING IT HAPPEN FOR PEOPLE

Although institutions for people with disabilities are designed to protect people with disabilities from society and from themselves, institutions are now identified as risk factors for violence, especially for sexual assault of women and girls with disabilities.<sup>41</sup> Thus, rather than finding protection in institutions, many women and girls with disabilities, especially those with psychosocial or cognitive disabilities, are subjected to rape, sexual abuse, physical abuse, and exploitation, as well as painful and involuntary treatment.<sup>42</sup> For this reason, the CRPD Committee has expressed concern about the use of institutionalization, generally, as a primary response for women and girls with disabilities who have been abandoned or abused.<sup>43</sup>

Moreover, the Special Rapporteur on the Rights of Persons with Disabilities has said specifically that forced sterilizations and forced abortion of women with disabilities are harmful and that discriminatory practices persist, particularly in, but not limited to, institutions.<sup>44</sup>

A study in Ukraine of women with psychosocial disabilities in psychiatric institutions, for example, found that most of the residents had been subjected to involuntary sterilization and forced abortions.<sup>45</sup> Another study, in Mexico, found that 42% of women

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WITH INTELLECTUAL DISABILITIES IN BOSNIA AND HERZEGOVINA, MONTENEGRO, SERBIA AND KOSOVO (2008).

41 Cf. DISABILITY RIGHTS INT'L & COLECTIVO CHUHCAN, TWICE VIOLATED: ABUSE AND DENIAL OF SEXUAL AND REPRODUCTIVE RIGHTS OF WOMEN WITH PSYCHOSOCIAL DISABILITIES IN MEXICO CITY (2015), <https://www.driadvocacy.org/wp-content/uploads/Mexico-report-English-web.pdf>.

42 ADAMS, *supra* note 40.

43 CRPD Comm., *Concluding Observations on the Initial Report of Costa Rica*, ¶ 29, U.N. Doc. CRPD/C/CRI/CO/1 (May 12, 2014); *Concluding Observations El Salvador*, *supra* note 20, ¶ 35.

44 Catalina Devandas (Special Rapporteur on the Rights of Persons with Disabilities), *Report of the Special Rapporteur on the Rights of Persons with Disabilities*, ¶¶ 29–31, U.N. Doc. A/72/133 (July 14, 2017) (providing guidance to States on how to ensure legal and policy frameworks that support sexual and reproductive health and rights of young women and girls with disabilities and address the structural factors that expose them to violence, abuse and other harmful practices).

45 See Laurie Ahern, *Ukraine Orphanages, Feeder for Human Trafficking*, HUFFINGTON POST: THE BLOG (2015), [http://www.huffingtonpost.com/laurie-ahern/ukraine-orphanages-feeder\\_b\\_7344882.html](http://www.huffingtonpost.com/laurie-ahern/ukraine-orphanages-feeder_b_7344882.html); DISABILITY RIGHTS INT'L, NO WAY HOME, THE EXPLOITATION AND ABUSE OF CHILDREN IN UKRAINE'S ORPHANAGES 21–23 (2015), <https://www.driadvocacy.org/wp-content/uploads/No-Way-Home-final2.pdf>; see also U.S. DEPT' OF STATE, 2014 TRAFFICKING IN PERSONS REPORT 390 (2014), <https://www.state>.



with psychosocial disabilities who were interviewed had experienced forced sterilizations or had been coerced by their families to undergo involuntary sterilizations, and that 40% of these interviewed women have suffered abuse while visiting a gynecologist, including sexual abuse and rape.<sup>46</sup>

Historically, forced sterilization and abortion were developed as part of the eugenics movement, which sought to prohibit the future birth of “unfit” persons.<sup>47</sup> Even today, involuntary sterilization and abortion have become accepted in some places as a way to protect women and girls with disabilities from menstruation, pregnancy, childbirth, and even from becoming parents, regardless of the views of the women themselves.<sup>48</sup> Such forced treatments, it is argued, are in the best interest of the girl or woman with a disability who should be “spared the difficulties” of menstruation, pregnancy, or childbirth.<sup>49</sup> Moreover, in the case of women and girls who are subjected to sexual abuse, forced sterilization is seen as a way to improve the quality of their future lives without the “burden” of pregnancy.<sup>50</sup> Accordingly, many women with disabilities throughout the world are subjected to forced treatment, including involuntary sterilization and forced abortions, to “protect” them from future

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gov/documents/organization/226849.pdf.

- 46 DISABILITY RIGHTS INT’L & COLECTIVO CHUHCAN, *supra* note 41, at 16, 18; *see also* HANDICAP INT’L, MAKING IT WORK INITIATIVE ON GENDER AND DISABILITY INCLUSION: ADVANCING EQUITY FOR WOMEN AND GIRLS WITH DISABILITIES 17, 18 (2015) (doing legal advocacy work for protecting the lives and integrity of women with disabilities detained at the Federico Mora Hospital in Guatemala).
- 47 *See* Buck v. Bell, 274 U.S. 200 (1927). *See also* Anna Arstein-Kerslake, *Understanding Sex, the Right to Legal Capacity to Consent to Sex*, 30 DISABILITY & SOC’Y 1459, 1460 (2015).
- 48 A now famous case, known as the Ashley X or Pillow Angel case, raises the question of whether it is medically and ethically permissible for parents to consent to stunt the growth of their young daughter who was born with significant developmental disabilities to prevent her from going through puberty by sterilizing her and subjecting her to estrogen therapy, a hysterectomy, and bilateral breast bud removal, in order to make it easier for them to care for her now and in the future. *See, e.g.*, S. Matthew Liao et al., *The Ashley Treatment: Best Interests, Convenience, and Parental Decision-Making* 37 HASTINGS CENTER REPORT 16 (Mar.–Apr. 2007); Steven D. Edwards, *The Ashley Treatment: A Step Too Far, or Not Far Enough?* 34 J. MED. ETHICS 341 (2007).
- 49 *See* Manjoo, *supra* note 17, ¶ 36; Roberta Cepko, *Involuntary Sterilization of Mentally Disabled Women*, 8 BERKELEY J. GENDER, L. & JUST. 123, 162–63 (2013).
- 50 *See* Manjoo, *supra* note 17, ¶ 36; Cepko, *supra* note 49, at 141.



pregnancy and motherhood.<sup>51</sup>

Despite such practices, research has found that involuntary sterilization and abortion neither protect women and girls with disabilities nor provide a legitimate excuse for the State to fail to prevent abuse and assault in the first instance.<sup>52</sup> For this reason, the United Nations Special Rapporteur on Torture has interpreted forced sterilization as a violation of the right to be free from torture and other cruel, inhuman, or degrading treatment or punishment.<sup>53</sup>

Women and girls with disabilities are also at risk of violence in jails and prisons. Like incarcerated women without disabilities, they are at risk of rape, threats of rape, unwanted touching, invasive body searches and forced disrobing, as well as insults and sexual humiliation.<sup>54</sup> The perpetrators of such violence may be other prisoners or prison staff.<sup>55</sup> As the World Health Organization has found, the threat of violence, such as that which is experienced by women in confinement, puts women and girls with disabilities at increased risk of physical danger, mental health crises, and even death.<sup>56</sup>

### III. Barriers that Women with Disabilities Who Experience Violence Face Seeking Access to Justice

In addition to the various forms of violence that women with disabilities face at home and in institutions, many women with disabilities face numerous, and often insurmountable, barriers in

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51 See Robyn M. Powell & Michael A. Stein, *Persons with Disabilities and Their Sexual, Reproductive and Parenting Rights: An International and Comparative Analysis*, 11 FRONTIERS L. CHINA 53, 59–68 (2016); see also HUMAN RIGHTS WATCH, COERCED STERILIZATION OF WOMEN AND GIRLS WITH DISABILITIES (Nov. 10, 2015), <https://www.hrw.org/news/2011/11/10/sterilization-women-and-girls-disabilities>; Corte Constitucional de Colombia [Constitutional Court of Colombia], Sentence C-182, April 13, 2016; Corte Constitucional de España [Constitutional Court of Spain], Sentence 215/1994, July 14, 1994 (allowing forced sterilizations of persons with disabilities).

52 See WORLD HEALTH ORG. ET AL., ELIMINATING FORCED, COERCIVE AND OTHERWISE INVOLUNTARY STERILIZATION: AN INTERAGENCY STATEMENT 6 (2014).

53 Juan E. Méndez (Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment), *Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, ¶ 48, UN Doc. A/HRC/22/53 (Feb. 1, 2013).

54 Manjoo, *supra* note 17, ¶ 50.

55 See *id.*

56 See WORLD HEALTH ORG., WORLD REPORT ON VIOLENCE AND HEALTH 5 (2002).

their efforts to access justice based on their status as both female and disabled.<sup>57</sup> In many countries today, women and girls with disabilities are denied equal treatment on the basis of their gender and their disability.<sup>58</sup> As such, women and girls with disabilities experience multiple and intersectional discrimination.<sup>59</sup> As women, they are denied equal treatment based on stereotypical attitudes and long held cultural beliefs about women in their respective societies.<sup>60</sup> And, as people with disabilities, they face additional discrimination because of their disabilities.<sup>61</sup> Thus, disabled women face unique challenges in accessing equal rights to health care, education, vocational rehabilitation, as well as the judicial system.<sup>62</sup> As Ortoleva and Lewis have written, “when gender and disability intersect, violence takes on unique forms, has unique causes, and results in unique consequences.”<sup>63</sup>

While multiple discrimination refers to a compounded or aggravated situation when a person is discriminated on two or several grounds,<sup>64</sup> intersectional discrimination refers to the situation in which several factors interact with each other at the same time and in such a way that they are inextricably linked.<sup>65</sup> Thus, women with

57 Int'l Network of Women with Disabilities, *Document on Violence against Women with Disabilities*, WOMEN WITH DISABILITIES AUSTL. 11 (Oct. 4, 2010), <http://wwda.org.au/wp-content/uploads/2013/12/inwwdviol2010.pdf>.

58 U.N. Enable, First Session of the Ad Hoc Comm., *Human Rights and Persons with Disabilities*, U.N. Doc. A/AC.26S/CRP2 (2002).

59 Comm. on the Elimination of Discrimination Against Women (CEDAW), *General Recommendation No. 28 on the Core Obligations of States Parties Under Article 2 of the CEDAW*, ¶ 18, U.N. Doc. CEDAW/C/GC/28 (2010); see also *General Comment No. 3: Article 6: Women and Girls with Disabilities*, *supra* note 7, ¶ 4(c).

60 Stephanie Ortoleva, *Women with Disabilities: The Forgotten Peace Builders*, 33 LOY. L.A. INT'L & COMP. L. REV. 83, 91 (2010).

61 ORTOLEVA & LEWIS, *supra* note 1, at 14, 26–27, 98.

62 See generally U.N. Enable, First Session of the Ad Hoc Comm., *Human Rights and Persons with Disabilities* (2001). See also Comm. on the Elimination of Discrimination Against Women (CEDAW), *General Recommendation No. 33: Women's Access to Justice*, ¶¶ 13, 17(g), U.N. Doc. CEDAW/C/GC/33 (Aug. 3, 2015).

63 ORTOLEVA & LEWIS, *supra* note 1, at 14.

64 Comm. on the Elimination of Discrimination Against Women (CEDAW), *General Recommendation No. 25 on Article 4, ¶ 1, of the Convention on the Elimination of All Forms of Discrimination Against Women, on Temporary Special Measures*, ¶ 12, U.N. Doc. HRI/GEN/1/Rev.7 (May 2004).

65 Comm. on the Elimination of Discrimination Against Women (CEDAW), *General Recommendation No. 28 on the Core Obligations of States Parties Under Article 2 of the CEDAW*, ¶ 18, U.N. Doc. CEDAW/C/GC/28 (Dec. 16, 2010). See also Kimberle Crenshaw, *Mapping the Margins: Intersectionality, Identity Politics and*

disabilities are affected by intersectional discrimination because they experience violence in a unique way due to at least two grounds of discrimination that interact with each other—as women and as persons with a disability.<sup>66</sup>

Women and girls with disabilities also experience discrimination as individuals with multidimensional layers of identities and life circumstances.<sup>67</sup> Women and girls with disabilities, like women and girls without disabilities, are not a homogenous group. They are women and girls of color, indigenous people, refugees, and migrants; lesbian, bisexual, transgender, and intersex; young and elderly; mothers, wives, and girlfriends; religious and atheist; some live in poverty and others are gainfully employed; some live at home with their families or choose to live alone; others live in nursing homes, residential institutions, or prisons.<sup>68</sup> Further, there are women with physical, developmental, or sensory disabilities; others with invisible psychosocial or intellectual disabilities; and still others with multiple disabilities requiring high levels of support, while others need no support at all. Although all of these women are at risk of violence, women who are deaf, blind, or deaf-blind, or who have a psychosocial or intellectual disability have been found to be most vulnerable to abuse<sup>69</sup> because of their isolation, dependency, and the stigma related to their particular disability.<sup>70</sup>

Consequently, each group of women and girls with disabilities may require different responses to the violence they experience. For example, a recent comparative report of countries in the European

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*Violence Against Women of Color*, 43 STAN. L. REV. 1241, 1248 (1991).

66 For instance, indigenous women with disabilities often faced high levels of alcoholism and substance abuse in their communities, cultural and linguistic barriers, lack of education and information, as well as poverty and conflicts between the traditional and contemporary justice system. See CRPD Comm., *Concluding Observation on the Initial Report of Mexico*, ¶¶ 10, 25, 33, U.N. Doc. CRPD/C/MEX/CO/1 (Oct. 27, 2014) [hereinafter *Concluding Observations Mexico*]; see also Doreen Demas, *Triple Jeopardy: Native Women with Disabilities*, 13 CAN. WOMAN STUD. 53, 53–55 (1989).

67 Comm. on the Elimination of Discrimination Against Women (CEDAW), *General Recommendation No. 19: Violence Against Women*, ¶ 16, U.N. Doc. A/47/38 (1993).

68 ORTOLEVA & LEWIS, *supra* note 1, at 14.

69 CRPD Comm., *Concluding Observations on the Initial Report of Brazil*, ¶ 14, U.N. Doc. CRPD/C/BRA/CO/1 (Sept. 29, 2015) [hereinafter *Concluding Observations Brazil*].

70 *General Comment No. 3: Article 6: Women and Girls with Disabilities*, *supra* note 9, ¶ 33.

Union found the following:

[W]omen with disabilities are at high risk to fall between two strands of support structures: Women's support mainstream services concerning domestic violence are often inaccessible for women with disabilities. At the same time, specific disability support services are often not prepared or lack awareness concerning gender-based violence. The gap in numbers of women with disabilities who have experienced violence and those having access to the justice system is significant. Only a few women with disabilities are in a position to assert their rights before courts.<sup>71</sup>

Moreover, for those women and girls with disabilities who live in countries where community and state mechanisms are weak or destroyed because of poverty, national disasters or conflicts, protection from violence by the state is not available. In addition, research has found that some of the obstacles women with disabilities face prevent them from seeking help. As a recent European report found:

Many women are brought up with a feeling of inferiority and the sense that they are not able to make any demands. Additionally, the reports show that persons with disabilities are often regarded as less credible and reliable by those in authority. Law enforcement, the judiciary and social workers often hold judgmental attitudes around women with disabilities' sexuality.<sup>72</sup>

Thus, for women with disabilities who wish to pursue legal action against a perpetrator, they face multiple barriers that do not exist for women without disabilities.<sup>73</sup>

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71 SABINE MANDL ET AL., LUDWIG BOLTZMANN INST. OF HUMAN RIGHTS, ACCESS TO SPECIALISED VICTIM SUPPORT SERVICES FOR WOMEN WITH DISABILITIES WHO HAVE EXPERIENCED VIOLENCE: FINAL SHORT REPORT II (Oct. 2014), [https://www.gla.ac.uk/media/media\\_394354\\_en.pdf](https://www.gla.ac.uk/media/media_394354_en.pdf).

72 *Id.* at 12.

73 *Id.*

Such barriers are particularly challenging for women with psychosocial or intellectual disabilities who are assumed to lack capacity.<sup>74</sup> As a result, these women may be unable to secure assistance by law enforcement or lawyers. Thus, like women without disabilities, women with disabilities must not only overcome fears related to testifying in court and participating in court proceedings, but they also face the additional stigma that attaches to them as victims of sexual assault or violence because they are women with disabilities. Moreover, rather than help victims of violence, the laws in many countries create legal barriers which deny access to justice for women with disabilities who seek to protect their rights, as discussed in the following section.

### **A. Denial of Legal Capacity and Equal Recognition Under Law**

In many countries women (and men) with psychosocial and intellectual disabilities are denied legal capacity and equal recognition under law.<sup>75</sup> Yet legal capacity is a necessary precondition for exercising one's fundamental human and civil rights, including the right to access justice. Without legal capacity, a woman (or man) with a disability will not be considered a person under law.<sup>76</sup> She cannot file a criminal or civil legal complaint, nor will she be permitted to testify as a witness or victim.<sup>77</sup> In such cases, the lack of legal capacity has been referred to as "civil death."<sup>78</sup>

The right to legal capacity and equal recognition under law are core principles of international human rights law. The Universal Declaration of Human Rights and the International Covenant on Civil and Political Rights (ICCPR) both specifically recognize the right to equal recognition before the law.<sup>79</sup> Article 4 of the ICCPR

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74 See *infra* Section III.A.

75 See generally KANTER, *supra* note 8, at 235–89.

76 *Id.* at 252.

77 See *id.* at 240, 242, 252–53.

78 *Id.* at 242; *Supported Decision Making in Theory and Practice: Ireland's Capacity Bill*, NUI GALWAY IRELAND (Apr. 29, 2013), [http://www.nuigalway.ie/cdlp/events/supported\\_decisionmaking\\_in\\_theory\\_practice.html](http://www.nuigalway.ie/cdlp/events/supported_decisionmaking_in_theory_practice.html); Gábor Gombos, *From Civil Death to Full Personhood: Ireland's Challenges to Implement the CRPD*, SLIDESHARE (Apr. 30, 2013), <https://www.slideshare.net/legislation/gabor-gombos-presentation>.

79 G.A. Res. 2200A (XXI), art. 3, International Covenant on Civil and Political Rights (Dec. 16, 1966) [hereinafter ICCPR]; G.A. Res. 217 (III) A, art. 6, Universal Declaration of Human Rights (Dec. 10, 1948).

goes so far as to state that there may be no derogation of the right to equal recognition before the law, even in times of public emergency.<sup>80</sup> Moreover, the right to equal recognition is also included in Article 15 of the CEDAW, which requires the recognition of women's legal capacity on an equal basis with men, including with respect to entering into contracts, administering property, and exercising their rights in the justice system.<sup>81</sup> Similarly, Article 3 of the African Charter on Human and Peoples' Rights recognizes the right of every person to equality before the law and the right to equal protection of the law.<sup>82</sup> Article 3 of the Inter-American Convention on Human Rights also includes the right to equal recognition for all people before the law.<sup>83</sup>

Without equal recognition under law, women with disabilities remain invisible to the legal system. They are unable to access information about their basic rights, how to exercise those rights, or how to receive accommodations, all of which are necessary to pursue their rights within the legal system. Moreover, based on outmoded views about the competency of people with disabilities, many women (and men) with intellectual or psychosocial disabilities are prevented from testifying in court, both as witnesses and victims. Alternatively, if they are allowed to testify, their testimony will be excluded as not credible.<sup>84</sup> In cases of sexual abuse, in particular, when the complaining witness' testimony is the only evidence to justify a conviction, the exclusion of such evidence is tantamount to a dismissal of all charges.<sup>85</sup> The CRPD recognizes the importance of equal recognition under law and legal capacity for people with

80 ICCPR, *supra* note 79, art. 4.

81 CEDAW, *supra* note 5, art. 15.

82 Organization of African Unity, African Charter on Human and Peoples' Rights (Banjul Charter), art. 3, June 27, 1981, 1520 U.N.T.S. 217, OAU Doc. CAB/LEG/67/3 rev. 5 [hereinafter Banjul Charter].

83 Organization of American States, American Convention on Human Rights (Pact of San José), art. 3, Nov. 22, 1969, O.A.S.T.S. No. 36, 1144 U.N.T.S. 123 [hereinafter Am. Convention on H.R.].

84 See OHCHR Annual Report, *supra* note 24, ¶¶ 41–42; see also JONATHON GOODFELLOW & MARGARET CAMILLERI, DISABILITY DISCRIMINATION LEGAL SERVICE, BEYOND BELIEF, BEYOND JUSTICE: THE DIFFICULTIES FOR VICTIMS/SURVIVORS WITH DISABILITIES WHEN REPORTING SEXUAL ASSAULT AND SEEKING JUSTICE 59 (2003); Women Enabled Int'l, Inc., *Women Enabled International's Comments to the Committee on the Rights of Persons with Disabilities' Draft General Comment on Article 6: Women 2* (2015).

85 See OHCHR Annual Report, *supra* note 24, ¶ 42; see also GOODFELLOW & CAMILLERI, *supra* note 84, at 59; Women Enabled Int'l, *supra* note 84, at 2.



disabilities in Article 12 of the CRPD, which guarantees equal recognition for all.<sup>86</sup> Yet, despite this provision in the CRPD, many countries' laws continue to deprive people with disabilities of legal capacity, as is discussed in a subsequent section of this article about legal reform in Peru.<sup>87</sup>

### ***B. Barriers to Accessing Courts and Other Institutions of the Justice System***

In addition to denial of legal capacity, another barrier that women with disabilities face when seeking to secure access to justice is the physical inaccessibility of the justice system, itself. Many courthouses throughout the world are inaccessible to people with mobility impairments since they lack ramps and wheelchair lifts.<sup>88</sup> These buildings also may lack accessible restrooms, witness chairs, and jury boxes, as well as the technology and other assistance required to allow persons who are deaf, blind, deaf-blind, or those with other non-motor disabilities to participate in judicial proceedings.<sup>89</sup>

Moreover, when women with disabilities want to end the cycle of violence by trying to report their abusers to the authorities, they often face obstacles in communicating with police and other law enforcement professionals. For instance, lack of accessibility of police or community abuse hotlines and the lack of sign language interpreters, assistive devices or information in Braille or plain

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86 See KANTER, *supra* note 8, at 251–59. For a complete discussion of the history of the drafting of Article 12 as well as information about its ratification history and implementation in various countries see *id.* at 235–89 (chapter 7, entitled “The Right to Legal Capacity and Equal Recognition of the Law Under Article 12”). For information about the implementation of Article 12 as a nationwide program to ensure legal capacity for all in Israel and other countries, see Arlene S. Kanter & Yotam Tolub, *The Fight for Personhood, Legal Capacity and Equal Recognition Under Law for People with Disabilities in Israel and Beyond*, 39 CARDOZO L. REV. 557 (2017).

87 See *infra* Section VI.

88 See *Tennessee v. Lane*, 541 U.S. 509, 533–34 (2004) (holding that the Americans with Disabilities Act requires all state courthouses to be accessible to people with disabilities); see generally U.S. ACCESS BOARD, JUSTICE FOR ALL: DESIGNING ACCESSIBLE COURTHOUSES (2006) (providing information about how the design of courthouses impeded the physical access to justice for people with disabilities).

89 Stephanie Ortoleva, *Inaccessible Justice: Human Rights, Persons with Disabilities and the Legal System*, 17 ILSA J. INT'L & COMP. L., 281, 305 (2011); see also HANDICAP INT'L, MAKING IT WORK SUBMISSION TO THE CRPD COMMITTEE: GENERAL RECOMMENDATION ON ARTICLE 6: WOMEN AND GIRLS WITH DISABILITIES, ¶ 8(A) (2015).



language text (for those who need easy-to-understand formats) may deter or even prevent a woman with certain disabilities from filing the required report.<sup>90</sup> Further, if the woman is able to pursue a case in court, the language used in the courtroom, such as leading questions typically used in cross-examinations, may be confusing to them.<sup>91</sup> Moreover, for women (as well as men) with intellectual disabilities, research has shown their propensity for pleasing their questioners may lead to false confessions and other false statements, thereby further undermining their ability to access justice.<sup>92</sup>

The millions of women with disabilities who live in poverty face additional obstacles. For them, “[d]isability is both a fundamental cause and consequence of income poverty.”<sup>93</sup> Thus, many women with disabilities who live in poverty may be unable to secure legal assistance,<sup>94</sup> which is often necessary to pursue legal claims against perpetrators of violence.

Moreover, in those cases in which a woman can successfully escape violence, she may be unable to find an accessible shelter or secure the accommodations she may need at a shelter, such as sign language interpreters, braille, or other accommodations.<sup>95</sup> One study in the United States, for example, found that 94% of domestic violence shelters could not accommodate the needs of women with disabilities.<sup>96</sup> Another study noted that only 35% of shelters could accommodate victims of violence with physical/mobility, cognitive, visual, and hearing impairments.<sup>97</sup> A third study in Canada found

90 See Ortoleva, *supra* note 89, at 300, 311; see also Manjoo, *supra* note 17, ¶¶ 59–62.

91 GOODFELLOW & CAMILLERI, *supra* note 84, at 61.

92 KANTER, *supra* note 8, at 226–27.

93 AM. BAR ASS'N: COMM. ON MENTAL AND PHYSICAL DISABILITY, ABA DISABILITY STATISTICS REPORT 3 (2010), <http://lawschoolasp.org/docs/2012/ABADisabilityStatisticsReport.pdf> (citing statistics by Shawn Fremstad from the Center for Economic and Policy Research).

94 Ortoleva, *supra* note 89, at 300.

95 DISABLED WOMEN'S NETWORK OF CAN., *supra* note 15, at n.xxxi (citing CAN. CTR. FOR JUSTICE STATISTICS, FAMILY VIOLENCE IN CANADA: A STATISTICAL PROFILE 15 (2009)); see also Karen Nutter, *Domestic Violence in the Lives of Women with Disabilities: No (Accessible) Shelter from the Storm*, 13 S. CAL. REV. L. & WOMEN'S STUD., 329, 344–45 (2004).

96 For excerpts, see Margaret A. Nosek & Carol A. Howland, *Abuse of Women with Disabilities: Policy Implications*, 8 J. DISABILITIES POL'Y STUD. 157 (1997), <https://www.bcm.edu/research/centers/research-on-women-with-disabilities/topics/violence/access-to-domestic-violence-programs>.

97 ELEANOR LYON ET AL., MEETING SURVIVORS' NEEDS: A MULTI-STATE STUDY OF DOMESTIC VIOLENCE SHELTER EXPERIENCES 7 (2008).

that “only about one-quarter (22%) of shelters provided TTY/TDD equipment (i.e., specially equipped telephones) for people who are hearing impaired; 17% provided sign language or interpretation services, 17% provided large print reading materials to people who are visually impaired and 5% provided Braille reading materials.”<sup>98</sup> In most countries in the world, therefore, not only are most shelters not accessible, but there is not even any data about the availability of shelters.

### C. Attitudinal Barriers

In addition to the legal and physical barriers to accessing the justice system, attitudinal barriers also make it difficult for women with disabilities who experience violence to exercise their right of access to justice. For example, a recent study of the International Disability Alliance found that women with psychosocial disabilities are often discredited as victims and witnesses, and are questioned, unnecessarily and excessively, about their ability to tell the truth.<sup>99</sup> Similarly, women with vision and hearing impairments may be perceived as unreliable because they cannot recount what they saw or heard.<sup>100</sup> Additionally, women with cognitive disabilities may have trouble remembering the sequence, place, or time of events, which can make them less credible as victims as well as witnesses.<sup>101</sup>

Further, judges and juries have been found to discount the testimony of women with disabilities, particularly in sexual abuse cases, because they do not see women with disabilities as capable of consenting or refusing to consent to sex.<sup>102</sup> Research has shown

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98 DISABLED WOMEN’S NETWORK OF CAN., *supra* note 15, at n.xxxi (citing CAN. CTR. FOR JUSTICE STATISTICS, FAMILY VIOLENCE IN CANADA: A STATISTICAL PROFILE 15 (2009)).

99 See generally Int’l Disability All., 54th session, *IDA Submission to the CEDAW Committee’s General Discussion on Access to Justice 2* (Feb. 18, 2013), <http://www.internationaldisabilityalliance.org/resources/submission-cedaw-committee%E2%80%99s-general-discussion-access-justice-54h-session> [hereinafter *IDA Submission*].

100 *Id.*; see also HOUSE OF LORDS HOUSE OF COMMONS JOINT COMMITTEE ON HUMAN RIGHTS, *A LIFE LIKE ANY OTHER? HUMAN RIGHTS OF ADULTS WITH LEARNING DISABILITIES: SEVENTH REPORT, 2007-8*, HC 73-II, at 68–70 (UK).

101 Manjoo, *supra* note 17, ¶¶ 41–42; see also Janine Benedet & Isabel Grant, *Hearing the Sexual Assault Complaints of Women with Mental Disabilities: Evidentiary and Procedural Issues*, 52 MCGILL L.J. 515, 531–32 (2007).

102 *IDA Submission*, *supra* note 99, at 2; see also Benedet & Grant, *supra* note 101, at 522–23.

that judges and juries may disregard complaints of sexual assault by women with disabilities because they view such women as inviting such conduct as a result of their hyper-sexuality or their lack of self-control.<sup>103</sup> For example, in *State v. Fourtin*, a Connecticut court overturned the conviction of a perpetrator of sexual abuse, concluding that the victim, a woman with physical and psychosocial disabilities, chose not to indicate her lack of consent.<sup>104</sup> According to the court, even if she could not speak, she should have been able to indicate her lack of consent by using “gestures, biting, kicking, and screaming.”<sup>105</sup> This decision has been criticized as reflecting a lack of understanding about the impact of sexual violence on women with disabilities.<sup>106</sup>

An additional risk for mothers with disabilities who try to report domestic violence is their fear of losing custody of their children. Although women without disabilities are also at risk for losing their children in such cases, women with disabilities face the additional stigma that attaches to being a parent with a disability.<sup>107</sup> Courts have been known to assume that the non-disabled husband, even an abuser, is a more competent parent simply because he is not disabled.<sup>108</sup> Even today, in the United States, one in ten children are at risk of being removed from their home by the state or are at risk of such removal because of their parents’ disability.<sup>109</sup> Further, 19% of children currently in foster care in the U.S. have a parent with a disability.<sup>110</sup>

103 IDA Submission, *supra* note 99, at 2; *see also* OHCHR Annual Report, *supra* note 24, ¶ 41.

104 *State v. Fourtin*, 52 A.3d 674, 676–77 (Conn. 2012).

105 *Id.* at 689–90.

106 *See generally* U.S. DEP’T OF JUST., NCJ 227814, NATIONAL CRIME VICTIMIZATION SURVEY: CRIME AGAINST PEOPLE WITH DISABILITIES 2007 (2009).

107 *See generally* E. Lightfoot et al., *The Inclusion of Disability as a Condition for Termination of Parental Rights*, 34 CHILD ABUSE & NEGLECT 927 (2010).

108 *See generally id.*

109 Robyn Powell, *Parents with Disabilities Face Uphill Battle to Keep Their Children*, PAC. STANDARD (Jan. 3, 2018), <https://psmag.com/social-justice/parents-with-disabilities-face-an-uphill-battle-to-keep-their-children> (citing 2012 NATIONAL DATA ON PARENTS WITH DISABILITIES AND THEIR CHILDREN, <https://www.lookingglass.org/national-services/research-a-development/127-additional-information-on-the-2012-national-data-on-parents-with-disabilities-and-their-children> (last visited Apr. 23, 2018)).

110 Elizabeth Lightfoot & Sharyn DeZelar, *The Experiences and Outcomes of Children in Foster Care who were Removed Because of a Parental Disability*, 62 CHILD. & YOUTH SERV. REV. 22 (2016).

In sum, in addition to legal and physical barriers, many conscious and unconscious attitudes and beliefs about women with disabilities by judges, police, and other persons involved in the justice system contribute to the continuing denial of access to justice for women and girls with disabilities who experience violence. Such denial of access to justice often forces them to remain in dangerous and abusive situations, providing impunity to the perpetrators; it also perpetuates the continuing invisibility of the problem of violence against women and girls with disabilities.<sup>111</sup>

#### **IV. International Human Rights Laws that Protect Women and Girls with Disabilities from Violence and their Right to Access Justice**

Given the history of violence against women and girls with disabilities and their difficulties accessing justice, one would assume that international legal protections have been developed to address such concerns. Yet, only recently has the issue of violence against women and girls with disabilities been identified as worthy of attention by the international community. Both the 1979 Convention on the Elimination of Discrimination Against Women (CEDAW) and the 1989 Convention on the Rights of the Child (CRC) prohibit violence against women and girls, respectively.<sup>112</sup> However, neither treaty mentions women and girls with disabilities. It was not until the adoption of the Convention on the Rights of Persons with Disabilities (CRPD) in 2006 that the rights of women and girls with disabilities, including their right to be free from violence and to access justice, are specifically protected under international human rights law.<sup>113</sup>

##### **A. *The Convention on the Elimination of Discrimination Against Women on Violence Against Women with Disabilities.***

The CEDAW is the first international human rights treaty to address the rights of women, in general, and in particular their

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111 OHCHR Annual Report, *supra* note 24, ¶¶ 19, 34, 41, 42, 44.

112 CEDAW, *supra* note 5, art. 6; CRC, *supra* note 6, art. 19(1).

113 See *infra* Section IV.C. See also, WOMEN ENABLED INT'L, ACCOUNTABILITY: U.N. STANDARDS ON GENDER-BASED VIOLENCE AGAINST WOMEN AND GIRLS WITH DISABILITIES (2018), <https://www.womenenabled.org/atk.html> (providing an in-depth summary of what U.N. treaty bodies have said about gender-based violence generally, and violence against women and girls with disabilities specifically).

right to be protected from discrimination. To date, the CEDAW has been ratified by 189 countries, but not the United States. Although CEDAW does not mention women with disabilities, specifically, it does protect the rights of all women to be free from discrimination, which includes the right to safety and the right to access justice.<sup>114</sup> CEDAW also seeks to prevent violence by calling for the adoption of laws and policies that address gender-based violence, which would include measures to eliminate stereotypes and cultural practices that contribute to violence against women with disabilities.<sup>115</sup> The prevention of violence, under CEDAW, therefore “include[s] the duty to transform patriarchal gender structures and values that perpetuate and entrench violence against women.”<sup>116</sup> Moreover, as the CEDAW Committee has noted, “States may also be responsible for private acts if they fail to act with due diligence to prevent violations of rights or to investigate and punish acts of violence.”<sup>117</sup>

In addition, Article 2 of the CEDAW requires States Parties to “ensure through competent national tribunals and other public institutions the effective protection of women against any act of discrimination.”<sup>118</sup> Article 2(f) also requires States Parties to “take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices which constitute discrimination against women.”<sup>119</sup> Further, Article 5(a) of the CEDAW requires States Parties to “modify social and cultural patterns of conduct” for achieving the elimination of prejudices and discriminatory practices.<sup>120</sup>

The CEDAW also requires equality of men and women before the law in Article 15.<sup>121</sup> Article 15(2) specifically provides

114 CEDAW, *supra* note 5, arts. 2, 11(f), 15(l).

115 Women Enabled Int’l, *Comments to the Committee on the Rights of Persons with Disabilities’ Draft General Comment on Article 6: Women*, WOMEN ENABLED 3 (July 24, 2015) <https://www.womenenabled.org/pdfs/WEI%20Submission%20--%20CRPD%20General%20Comment%20on%20Article%206%20-%20Women%20July%202024,%202015%20FINAL.pdf>.

116 Yakin Ertürk (Special Rapporteur on Violence Against Women), *Report of the Special on Violence Against Women, its Causes and Consequences*, ¶ 15, U.N. Doc. E/CN.4/2006/61 (Jan. 20, 2006).

117 *General Recommendation No. 19: Violence against Women*, *supra* note 67, ¶ 19.

118 CEDAW, *supra* note 5, art. 2(c).

119 *Id.* art. 2(f).

120 *Id.* art. 5.

121 *Id.* art. 15. Iceland became the first Nordic country to require employers to pay women the same as men. It also requires companies to proactively get equal pay certification from the government. Interestingly, although most

for women's legal capacity on an equal basis with men, thereby acknowledging that recognition of legal capacity is integral to equal recognition before the law:

States Parties shall accord to women, in civil matters, a legal capacity identical to that of men and the same opportunities to exercise that capacity. In particular, they shall give women equal rights to conclude contracts and to administer property and shall treat them equally in all stages of procedure in courts and tribunals.<sup>122</sup>

This provision applies to all women, including women with disabilities. Article 15(2) also requires States Parties to recognize legal capacity for men and women and that men and women must be provided with the same opportunities to exercise that capacity, including equal treatment in all stages of court and tribunal procedures.<sup>123</sup>

Moreover, soon after the adoption of the CEDAW, in 1993, the United Nations adopted the Declaration on the Elimination of Violence Against Women (DEVAW). This Declaration defines violence against women as an "act of gender-based violence that results in, or is likely to result in, physical, sexual or psychological harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life."<sup>124</sup> It applies to women with and without disabilities.

In addition, in 2000, the United Nations General Assembly proclaimed that "girls and women of all ages with any form of disability are generally among the more vulnerable and marginalized

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countries have laws that prohibit discrimination based on gender, including in employment, research shows the legislation is far from effective and that even today, women are paid less than men in every country in the world, according to research by the World Economic Forum. See Ivana Kottasova, *Iceland Makes it Illegal to Pay Women Less Than Men*, CNN MONEY (Jan. 3, 2018, 12:14 PM), <http://money.cnn.com/2018/01/03/news/iceland-gender-pay-gap-illegal/index.html>.

122 CEDAW, *supra* note 5, art. 15(2).

123 *Id.* art. 15(2).

124 G.A. Res. 48/104, art. 1, Declaration on the Elimination of Violence against Women (Dec. 20, 1993), <http://www.un.org/documents/ga/res/48/a48r104.htm>.



of society.”<sup>125</sup> Since then, the issue of violence against women and girls with disabilities has continued to garner attention on the international stage.

For example, in 2011, the United Nations Human Rights Council requested the Office of the High Commissioner for Human Rights to prepare a study on violence and disability, recognizing that disability can be both a cause and consequence of violence against women with disabilities.<sup>126</sup> Further, in 2012, the UN Special Rapporteur on Violence Against Women issued a report in which she explained that violence against women with disabilities is different and more severe than violence against girls and women without disabilities.<sup>127</sup> As the Special Rapporteur explained, for women and girls with disabilities, violence can be of a “physical, psychological, sexual or financial nature including neglect, social isolation, entrapment, degradation, detention, denial of health care, forced sterilization and psychiatric treatment.”<sup>128</sup> The Special Rapporteur noted that violence against women with disabilities has unique causes, including violence that is perpetuated by stereotypes about women with disabilities “that attempt to dehumanize or infantilize, exclude or isolate them, and target them for sexual and other forms of violence.”<sup>129</sup>

In addition to these United Nations pronouncements, the CEDAW Committee has adopted General Recommendations which address the rights of women with disabilities, including their right to be free from violence. General Recommendation Number 18, for example, requests States Parties to provide information about the situation of women with disabilities in their country reports, including measures taken for ensuring their equal access to

125 G.A. Res. S-23/3, *supra* note 3, ¶ 63.

126 Human Rights Council Res. 14/12, U.N. Doc. 17/ A/HRC/17/L.6 (June 10, 2011), <https://documents-dds-ny.un.org/doc/UNDOC/LTD/G11/140/17/PDF/G1114017.pdf?OpenElement>. The Resolution states, in pertinent part: “Invites the Office of the High Commissioner to prepare a thematic analytical study on the issue of violence against women and girls and disability, in consultation with the Special Rapporteur on violence against women, its causes and consequences, the Special Rapporteur on disability of the Commission for Social Development of the Economic and Social Council, other relevant special procedure mandate holders, States, United Nations entities, regional organizations, civil society organizations and other relevant stakeholders, and to report to the Human Rights Council at its twentieth session.” *Id.* ¶ 11.

127 Manjoo, *supra* note 17.

128 *Id.* ¶¶ 13, 31.

129 *Id.*



education and employment, health services, and social security.<sup>130</sup> General Recommendation Number 18 also instructs States Parties to indicate how they ensure the participation of women in all areas of social and cultural life, including their access to justice.<sup>131</sup>

Further, the CEDAW Committee has specifically recognized gender-based violence as a form of discrimination in its General Recommendation Number 19 of 1992.<sup>132</sup> To address family violence, the Committee recommends criminal penalties, civil remedies, rehabilitation, and support services.<sup>133</sup> In addition, the Committee recommends protective and support services for victims, gender-sensitive training of judicial and law-enforcement officers, statistics and research on the causes and effects of violence, and effective complaints procedures or remedies.<sup>134</sup>

General Recommendation Number 19 also provided the grounds for a decision by the CEDAW Committee in its first domestic violence case. In *A.T. v. Hungary*, the CEDAW Committee decided a case brought by a woman against Hungary for its failure to protect her from her abusive husband.<sup>135</sup> In a lengthy decision documenting the abuse the woman had suffered as well as the prohibition against discrimination in the CEDAW, the Committee concluded that gender-based violence was included in the definition of discrimination. The Committee relied on several articles of the CEDAW to support its decision, including Article 2 (Policy measures), Article 5 (Sex role stereotyping and prejudice), and Article 16 (Equality in marriage and family life). The Committee reasoned that when violence against a woman occurs, “States may also be responsible for private acts if they fail to act with due diligence to prevent violations of rights or to investigate and punish acts of violence, and for providing compensation.”<sup>136</sup> Thus although the CEDAW may not explicitly

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130 Comm. on the Elimination of Discrimination Against Women (CEDAW), *General Recommendation No. 18: Disabled Women*, ¶¶ 2–7, U.N. Doc. A/46/38 (1991).

131 *Id.*

132 *General Recommendation No. 19: Violence against Women*, *supra* note 67, ¶ 1.

133 *Id.* ¶ 23.

134 *Id.* ¶ 24 (a)–(b), (r)–(v).

135 Ms. A.T. v. Hungary, Communication No. 2/2003, Views of the Committee on the Elimination of Discrimination Against Women under Article 7, paragraph 3 of the Optional Protocol to the Convention on the Elimination of All Forms of Discrimination against Women (Jan. 26, 2005), <http://www.un.org/womenwatch/daw/cedaw/protocol/decisions-views/CEDAW%20Decision%20on%20AT%20vs%20Hungary%20English.pdf>.

136 *General Recommendation No. 19: Violence Against Women*, *supra* note 67, ¶ 9

prohibit violence, the Committee found that its occurrence may breach specific rights contained in the treaty.<sup>137</sup> Moreover, as the first domestic violence complaint submitted to and reviewed by the CEDAW Committee, *A.T. v. Hungary* makes clear that the CEDAW applies to state as well as non-state actors. According to this case, therefore, all State Parties to CEDAW are now required to view domestic violence as a form of gender-based discrimination and to create effective domestic remedies to address such violence as well as address the harmful gender stereotypes that contribute to inadequate responses by public officials when such violence occurs.

In 2015, the CEDAW Committee issued another important General Recommendation, Number 33, which recognizes that access to justice is essential for the achievement of gender equality. Further, because the Committee recognizes that women with disabilities face many physical and other barriers in accessing the justice system, the Committee also recommends specifically that States Parties pay special attention to access to justice for women with disabilities.<sup>138</sup>

Similarly, in 2017, the CEDAW Committee issued General Recommendation Number 35, which requires States Parties to repeal provisions that tolerate or condone forms of gender-based violence against women, including provisions allowing medical procedures to be performed on women with disabilities without their informed consent.<sup>139</sup> This Recommendation covers “laws that prevent women from reporting gender-based violence, such as guardianship laws that deprive women of legal capacity or restrict the ability of women with disabilities to testify in court.”<sup>140</sup> To address the challenges that women with disabilities experience in seeking redress for violence, the CEDAW Committee also recommends that States Parties provide “accessible protective mechanisms to prevent violence, including removal of communication barriers for victims with disabilities, and dissemination of information through accessible media.”<sup>141</sup>

In addition to its General Recommendations, the CEDAW

(addressing equality in family and marriage).

137 *Id.*

138 Comm. on the Elimination of Discrimination Against Women (CEDAW), *General Recommendation No. 33: Women’s Access to Justice*, ¶¶ 13, 17(g), U.N. Doc. CEDAW/C/GC/33 (Aug. 3, 2015).

139 Comm. on the Elimination of Discrimination Against Women (CEDAW), *General Recommendation No. 35: Gender-Based Violence Against Women*, ¶ 29(c)(i)–(iii), U.N. Doc. CEDAW/C/GC/35 (July 14, 2017).

140 *Id.*

141 *Id.* ¶ 31 (a)(ii)(d).

Committee has addressed the issue of barriers women with disabilities face in accessing justice in its concluding observations that it has submitted in response to various country reports.<sup>142</sup> In these concluding observations, the CEDAW Committee requests that States Parties give special attention to the issue of access to justice for women with disabilities. For example, the CEDAW Committee has recommended that the Philippines, Mali, Haiti, and Uganda work to ensure more effective access to justice for women who are victims of violence.<sup>143</sup> In response to the Philippines' country report, for example, the Committee recommends that the State Party should:

(a) Ensure that justice systems, both formal and informal, do not discriminate against women and are secure, affordable and physically accessible for women, including those who face intersecting forms of discrimination, such as by institutionalizing accessibility for women with all forms of disabilities, and raise awareness among women about all available justice systems.

(b) Take measures, including the development of capacity-building programmes for justice system personnel, in order to strengthen gender responsiveness and gender sensitivity . . . .<sup>144</sup>

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142 Concluding Observations are provided to a country by the relevant UN treaty Committee after the Committee has reviewed the country's report and prepared its list of issues. For information on the CEDAW Committee Concluding Observations, see U.N. OFFICE OF THE HIGH COMM'R FOR HUMAN RIGHTS, [https://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/TBSearch.aspx?TreatyID=3&DocTypeID=5](https://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?TreatyID=3&DocTypeID=5) (last visited July 16, 2018).

143 Comm. on the Elimination of Discrimination Against Women (CEDAW), *Concluding Observations on the Combined Sixth and Seventh Periodic Reports of Mali*, ¶¶ 39–40, U.N. Doc. CEDAW/C/MLI/CO/6-7 (July 25, 2016); Comm. on the Elimination of Discrimination Against Women (CEDAW), *Concluding Observations on the Combined Eighth and Ninth Periodic Reports of Haiti*, ¶¶ 41–42, U.N. Doc. CEDAW/C/HTI/CO/8-9 (Mar. 9, 2016); Comm. on the Elimination of Discrimination Against Women (CEDAW), *Concluding Observations of the Committee on the Elimination of Discrimination Against Women Uganda*, ¶¶ 45–46, U.N. Doc. CEDAW/C/UGA/CO/7 (Oct. 22, 2010).

144 Comm. on the Elimination of Discrimination Against Women (CEDAW), *Concluding Observations on the Combined 7th and 8th Periodic Reports of the Philippines*, ¶ 16, U.N. Doc. CEDAW/C/PHL/CO/7-8 (July 25, 2016).

In sum, since the adoption of the CEDAW, the CEDAW Committee has begun to address the issue of violence of women with disabilities and their access to justice. Hopefully, women with disabilities will become more fully integrated into the work and attention of the CEDAW Committee so that women with and without disabilities will enjoy the full protection of the CEDAW on an equal basis.

### ***B. The Convention on the Rights of the Child on Violence Against Girls with Disabilities***

The Convention on the Rights of the Child (CRC) was adopted in 1989.<sup>145</sup> To date, it is the most widely ratified human rights treaty.<sup>146</sup> Every country in the world, except the United States, has ratified the CRC. Article 23 of the CRC recognizes that children with disabilities “should enjoy a full and decent life,” recognizing their “special needs.”<sup>147</sup> In addition, Article 19(1) of the CRC discusses violence against children, although not specifically children with disabilities.<sup>148</sup> This article requires States Parties to “take appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child.”<sup>149</sup>

The CRC Committee also has addressed the vulnerability of children with disabilities in the Committee’s concluding observations in response to country reports and in its General Comments. In its concluding observations in response to Cuba’s country report, for example, the CRC Committee calls on Cuba to strengthen its efforts to combat gender stereotypes, which it sees as an important measure for preventing gender-based violence.<sup>150</sup> In addition, the CRC

145 CRC, *supra* note 6.

146 *Status of Ratification, Interactive Dashboard*, U.N. OFFICE OF THE HIGH COMM’R FOR HUMAN RIGHTS, <http://indicators.ohchr.org/> (last updated June 7, 2018); see also *The Convention on the Rights of the Child*, UNICEF, <https://www.unicef.org/crc> (last visited Apr. 23, 2018).

147 CRC, *supra* note 6, art. 23.

148 *Id.* art. 19.

149 CRC, *supra* note 6, art.19(1).

150 CRC Comm., *Concluding Observations: Cuba*, ¶¶ 24–25, U.N. Doc. CRC/C/CUB/CO/2 (Aug. 3, 2011).

Committee has required other States Parties, such as Afghanistan, to establish effective and child-friendly procedures and mechanisms to receive, monitor, and investigate complaints of sexual abuse and violence.<sup>151</sup>

Further, in its *General Comment Number 9*, the CRC Committee notes that children with disabilities are more vulnerable than other children “in all settings, including in the family, schools, private and public institutions, work environments, and the community at large.”<sup>152</sup> Accordingly, the Committee requests that States Parties “establish an accessible, child-sensitive complaint mechanism and a functioning monitoring system.”<sup>153</sup>

In addition, in its *General Comment Number 13*, the CRC Committee notes that children with disabilities experience particular forms of violence that children without disabilities do not typically experience. These forms of violence include:

- (a) Forced sterilization, particularly girls;
- (b) Violence in the guise of treatment (for example electroconvulsive treatment (ECT) and electric shocks used as “aversion treatment” to control children’s behaviour); and
- (c) Deliberate infliction of disabilities on children for the purpose of exploiting them for begging in the streets or elsewhere.<sup>154</sup>

In *General Comment 13*, the Committee also calls on State Parties to establish juvenile or family specialized courts and criminal procedures for child victims of violence and to provide accommodations for children with disabilities in the judicial process to ensure their equal participation.<sup>155</sup>

### **C. *The Convention on the Rights of Persons with Disabilities and Violence Against Women and Girls with Disabilities***

The Convention on the Rights of Persons with Disabilities

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151 CRC Comm., *Concluding Observations: Afghanistan*, ¶ 71, U.N. Doc. CRC/C/AFG/CO/1 (Apr. 8, 2011).

152 CRC Comm., *General Comment No. 9: Article 23: The Rights of Children with Disabilities*, ¶ 42, U.N. Doc. CRC/C/GC/9 (Feb. 27, 2007).

153 *Id.* ¶ 43(g).

154 CRC Comm., *General Comment No. 13: Article 19: The Rights of Children to Freedom of All Forms of Violence*, ¶ 23, U.N. Doc. CRC/C/GC/13 (Apr. 18, 2011).

155 *Id.* ¶¶ 48, 56.

(CRPD) was adopted in 2006, and entered into force in May 2008.<sup>156</sup> To date, 177 countries have ratified it and 92 countries have ratified its Optional Protocol.<sup>157</sup> Although the United States signed the CRPD in 2009, the U.S. Senate has failed on two occasions to secure the necessary two-third majority votes needed for ratification.<sup>158</sup>

The CRPD not only clarifies that all existing rights under international law must now apply to people with disabilities, but it also creates certain additional rights that had not been recognized previously under international law.<sup>159</sup> As such, the CRPD is the first binding treaty in the history of the United Nations to take into account the specific needs of persons with disabilities, including women and girls with disabilities and their risk of violence, abuse, and exploitation.

One of the most significant aspects of the CRPD is its inclusion of the social model of disability. Traditionally, disability has been seen only as a medical problem. People with disabilities were considered in need of medical care, charity, and protection but not equal rights.<sup>160</sup> By contrast, the social model of disability does not regard a person's disability as an inherent flaw in the person but rather the result of structural, environmental, communication, legal, and attitudinal barriers.<sup>161</sup> It is these barriers that "disable" the person with a disability from interacting with his or her society on an equal basis with others without disabilities.<sup>162</sup> Thus, the CRPD defines disability from a human rights-based approach, as an evolving concept that is generated by "the interaction between persons with impairments and attitudinal and environmental barriers that hinders

156 CRPD, *supra* note 8; *Entry into Force*, U.N. DEP'T OF ECON. & SOCIAL AFFAIRS, <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/entry-into-force.html> (last visited Apr. 23, 2018).

157 CRPD, U.N. DEP'T OF ECON. & SOCIAL AFFAIRS, <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> (last visited Apr. 23, 2018).

158 See Arlene S. Kanter, *The Failure of the United States to Ratify the CRPD*, in *RECOGNISING RIGHTS IN DIFFERENT CULTURAL CONTEXTS: THE UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES* (Kelley Johnson & Emily Kakoullis eds., forthcoming 2018).

159 KANTER, *supra* note 8, at 9.

160 *Id.* at 21–64.

161 Arlene S. Kanter, *The Law: What's Disability Studies Got to Do with It or an Introduction to Disability Legal Studies*, 42 COLUM. HUM. RTS. L. REV. 403, 426–28 (2011).

162 *Id.*



their full and effective participation in society on an equal basis with others.”<sup>163</sup>

The CRPD refers to violence against women and girls with disabilities in several different articles. In the Preamble, it states that “women and girls with disabilities are often at greater risk, both within and outside the home of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation.”<sup>164</sup> The Preamble also suggests that a “gender perspective” should be incorporated into “all efforts to promote the full enjoyment of human rights and fundamental freedoms by persons with disabilities.”<sup>165</sup> In addition, in Article 3 of the General Principles, the CRPD recognizes the principle of “equality between men and women.”<sup>166</sup> In addition to these articles, Articles 6 and 16, respectively, address the rights of women with disabilities, generally, and their right to be free from violence, in particular, as discussed in the next sections.

### 1. *Article 6 of the CRPD*

At the outset of the drafting process, it was unclear whether the drafters would support a separate article on women and girls with disabilities. Some of the participants questioned the need for a separate article on women and girls with disabilities, since they are included as women in the CEDAW, as children in the CRC, and as people with disabilities in the CRPD.<sup>167</sup> However, others argued that a separate article on women and girls in the CRPD was necessary due to the unique and different forms of discrimination that women and girls with disabilities experience, as compared to boys and men with disabilities.<sup>168</sup> This view prevailed.<sup>169</sup> The CRPD includes a separate article on women and girls, Article 6, titled Women with

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163 CRPD, *supra* note 8, pmb., para. e.

164 *Id.* pmb., para. q.

165 *Id.* pmb., para. s.

166 *Id.* art. 3.

167 See Sigrid Arnade & Sabine Haefner, *Standard Interpretation of the UN Convention on the Rights of Persons with Disabilities (CRPD) from a Female Perspective*, UNITED NATIONS OFFICE OF THE HIGH COMM’R FOR HUMAN RIGHTS 11 (May 2011), [http://www.ohchr.org/Documents/HRBodies/CRPD/DGD/2013\\_Submissions/1.NetzwekArtikel.doc](http://www.ohchr.org/Documents/HRBodies/CRPD/DGD/2013_Submissions/1.NetzwekArtikel.doc); Mi Yeon Kim, *Women with Disabilities: The Convention Through the Prism of Gender*, in HUMAN RIGHTS AND DISABILITY ADVOCACY 113, 120–22 (Maya Sabatello & Marianne Schulze eds., Univ. of Pa. Press 2014).

168 Kim, *supra* note 167, at 119.

169 *Id.* at 125.



Disabilities.<sup>170</sup> Article 6 provides as follows:

1. States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.
2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.<sup>171</sup>

Article 6 is a reflection of the CRPD's commitment to address the multiple and intersectional discrimination that women and girls with disabilities face. Article 6 recognizes that, because women and girls with disabilities are subject to multiple discrimination, States Parties are required to "take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms."<sup>172</sup> Article 6 also requires States Parties to "take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention."<sup>173</sup>

## 2. *Article 16 of the CRPD*

Although Article 6 of the CRPD addresses the rights of women and girls with disabilities, generally, it does not address their right to be free from violence and exploitation. Article 16 requires States Parties to "take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, from all forms of exploitation, violence and abuse, including their gender-based aspects."<sup>174</sup> Article 16(2) specifically requires States Parties to

<sup>170</sup> CRPD, *supra* note 8, art. 6.

<sup>171</sup> *Id.*

<sup>172</sup> *Id.*

<sup>173</sup> *Id.*

<sup>174</sup> *Id.* art. 16.

take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.”<sup>175</sup> Further, Article 16(3) provides that, “[i]n order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.”<sup>176</sup>

The growing importance attached to reparations for victims of violence, abuse and exploitation, is best expressed in Article 16(4), which calls on States Parties to:

[T]ake all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.<sup>177</sup>

Moreover, Article 16(5) goes even further to require States Parties to adopt “legislation and policies that identify, investigate, and prosecute” cases of violence against women and children with disabilities.<sup>178</sup> In fact, the CRPD Committee has explained that under Article 16, States Parties have an obligation to exercise due diligence

<sup>175</sup> *Id.* art. 16, ¶ 2.

<sup>176</sup> CRPD, *supra* note 8, art. 16, ¶ 3.

<sup>177</sup> *Id.* art. 16, ¶ 4.

<sup>178</sup> *Id.* art. 16, ¶ 5.

by investigating,<sup>179</sup> prosecuting,<sup>180</sup> and punishing<sup>181</sup> perpetrators of violence against women with disabilities, and to ensure effective remedies for the victims, including compensation and reparations.<sup>182</sup> The Special Rapporteur on Violence Against Women has developed a guide for the application of the due diligence standard for the prosecution of cases of violence and the reparations to which women and girls with disabilities are entitled.<sup>183</sup>

### 3. Articles 13 and 12 of the CRPD

In addition to the articles of the CRPD that address issues affecting the rights of women and girls, as discussed above, the CRPD also includes a specific article on access to justice that applies equally to women and girls who seek redress and protection from violence. In fact, the CRPD is the first international human rights treaty that includes “access to justice” as a separate substantive right.<sup>184</sup> Prior

179 See, e.g., CRPD Comm., *Concluding Observations on the Initial Report of Argentina*, ¶ 30, U.N. Doc. CRPD/C/ARG/CO/1 (Oct. 8, 2012) [hereinafter *Concluding Observations Argentina*]; *Concluding Observations China*, *supra* note 19, ¶¶ 58, 66; *Concluding Observations Gabon*, *supra* note 39, ¶ 39; CRPD Comm., *Concluding Observations on the Initial Report of Ukraine*, ¶ 12, U.N. Doc. CRPD/C/UKR/CO/1 (Oct. 2, 2015) [hereinafter *Concluding Observations Ukraine*].

180 See, e.g., *Concluding Observations Argentina*, *supra* note 179, ¶ 30; CRPD Comm., *Concluding Observation on the Initial Report of Hungary*, ¶ 32, U.N. Doc. CRPD/C/HUN/CO/1 (Oct. 22, 2012) [hereinafter *Concluding Observations Hungary*]; CRPD Comm., *Concluding Observations on the Initial Report of Turkmenistan*, ¶ 30, U.N. Doc. CRPD/C/TKM/CO/1 (May 13, 2015).

181 See, e.g., CRPD Comm., *Concluding Observations on the Initial Report of Ecuador*, ¶ 31, U.N. Doc. CRPD/C/ECU/CO/1 (Oct. 27, 2014) [hereinafter *Concluding Observations Ecuador*]; *Concluding Observations Mauritius*, *supra* note 21, ¶¶ 12, 28; *Concluding Observations Ukraine*, *supra* note 179, ¶ 12.

182 See, e.g., *Concluding Observations Kenya*, *supra* note 39, ¶ 31(b); *Concluding Observations Mexico*, *supra* note 66, ¶ 34; CRPD Comm., *Concluding Observations on the Initial Report of Mongolia*, ¶ 27, U.N. Doc. CRPD/C/MGN/CO/1 (May 13, 2015) [hereinafter *Concluding Observations Mongolia*]; CRPD Comm., *Concluding Observations of the Committee on the Rights of Persons with Disabilities in Peru*, ¶ 15, U.N. Doc. CRPD/C/PER/CO/1 (May 16, 2012) [hereinafter *Concluding Observations Peru*].

183 Yakin Ertürk (Special Rapporteur on Violence Against Women, its Causes and Consequences), *Report on the Due Diligence Standard as a Tool for the Elimination of Violence Against Women*, ¶¶ 74–99, U.N. Doc. E/CN.4/2006/61 (Jan. 20, 2006).

184 KANTER, *supra* note 8, at 222. See also Annual Rep. of the Office of the U.N. High Comm’r for Human Rights, Thematic Study on the Right to Access to Justice under Article 13 of the Convention on the Rights of Persons with Disabilities, U.N. Doc. A/HRC/37/25 (Dec. 27, 2017), [http://ap.ohchr.org/documents/dpage\\_e.aspx?si=A/HRC/37/25](http://ap.ohchr.org/documents/dpage_e.aspx?si=A/HRC/37/25) (providing guidance for the implementation of Article 13, identifying good practices, and making

to the CRPD, access to justice was recognized in other treaties only as “access to fair trial,” “equal protection of the law,” or as part of the “right to an effective remedy.”<sup>185</sup> Article 13 of the CRPD refers to access to justice in additional contexts, including legal, physical, and communication access, by providing the following:

1. States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.

2. In order to help to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff.<sup>186</sup>

Article 13 of the CRPD, therefore, makes clear that States Parties must ensure that all people with disabilities, including women and girls, have standing to access judicial proceedings on their own behalf. To achieve this goal, the legal capacity of women with disabilities must be ensured. The CRPD, therefore, also guarantees, for the first time in international human rights law, the right of all people with disabilities to legal capacity.

Interestingly, when the CRPD was drafted, Article 13 was Article 12, entitled Equal Recognition Before the Law. As the drafters negotiated the final version of Article 12, Article 13 was split off as a separate article.<sup>187</sup> Currently, Article 12 of the CRPD provides the following:<sup>188</sup>

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recommendations).

185 The access to justice and due process guarantees are protected by the following treaties, among others: ICCPR, *supra* note 79, art. 2, ¶ 14; European Convention on Human Rights, art. 6, ¶ 13, Nov. 4, 1950, 213 U.N.T.S. 222; Am. Convention on H.R., *supra* note 83, art. 8; Banjul Charter, *supra* note 82, art. 7.

186 CRPD, *supra* note 8, art. 13.

187 See KANTER, *supra* note 8, at 229–31.

188 For a comprehensive analysis of the history of the drafting of Article 12 and

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law . . . .<sup>189</sup>

Under Article 12, women as well as men with disabilities are entitled to legal capacity and have the right to make their own decisions and to exercise their rights under law.<sup>190</sup> Because certain jurisdictions have higher rates of imposing guardians or substitute decision-makers on women than on men, the CRPD Committee also acknowledges that “it is particularly important to reaffirm that the legal capacity of women with disabilities should be recognized on an equal basis with others.”<sup>191</sup> Moreover, in order to seek enforcement of their rights and obligations on an equal basis with others, women (and men) with disabilities must be recognized as persons before the law with equal standing in courts and tribunals. According to the CRPD Committee, States Parties therefore must also “ensure that

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its impact worldwide, see KANTER, *supra* note 8, at 238.

189 CRPD, *supra* note 8, art. 12.

190 See Catalina Devandas (Special Rapporteur on the Rights of Persons with Disabilities), *Report of the Special Rapporteur on the Rights of Persons with Disabilities*, U.N. Doc. A/HRC/37/56 (Dec. 12, 2017) (providing guidance to States on how to guarantee the right of persons with disabilities to equal recognition before the law, paying particular attention to the process of law reform on legal capacity).

191 CRPD Comm., *General Comment No. 1: Article 12: Equality Before the Law*, ¶ 35, U.N. Doc. CRPD/C/GC/1 (May 19, 2014).

persons with disabilities have access to legal representation on an equal basis with others.”<sup>192</sup>

One of the most fundamental rights of any person is the right to participate in the judicial process, as a litigant or witness.<sup>193</sup> In this context, the CRPD Committee notes that police officers, social workers, and judges and other court personnel must be trained to afford persons with disabilities the same credibility regarding their complaints and statements as is enjoyed by people without disabilities.<sup>194</sup> In addition, the CRPD Committee has explained that, in order to ensure that persons with disabilities can exercise their right to access justice, including testifying and pursuing legal remedies, States Parties must provide support in their exercise of legal capacity in various forms “including recognition of diverse communication methods, allowing video testimony in certain situations, procedural accommodation, the provision of professional sign language interpretation and other assistive methods.”<sup>195</sup>

In addition to the accommodations and supports that must be available to women (and men) who seek access to the justice system, Articles 12 and 13 impose on States Parties an affirmative duty to provide them with procedural and age-appropriate accommodations in order to facilitate their role as direct and indirect participants in legal proceedings, including during the investigative and other preliminary stages.<sup>196</sup>

#### 4. Article 9 of the CRPD

Article 9’s requirement of physical and communication accessibility applies to all children and adults with disabilities, including women and girls.<sup>197</sup> With respect to access to justice, it requires States Parties to ensure the accessibility of buildings and other facilities open to the public, including courthouses.<sup>198</sup> Not

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192 *Id.* ¶ 38.

193 IDA Submission, *supra* note 99, at 6; *see also* CRPD Comm., *Rules of Procedure*, r. 68(2), U.N. Doc. CRPD/C/4/2 (Aug. 13, 2010) (establishing that the CRPD Committee shall recognize the legal capacity of the author or victim before the Committee, regardless of whether the capacity is recognized in the State Party against which the communication is directed).

194 *General Comment No. 1: Article 12: Equality Before the Law*, *supra* note 191, ¶ 39.

195 *Id.* ¶ 39.

196 *See* KANTER, *supra* note 8, at 222.

197 CRPD, *supra* note 8, art. 9.

198 *Id.* (ensuring persons with disabilities access, on an equal basis with others, to the physical environment, transportation, information and communications,

only must the buildings themselves be physically accessible, but the services, information, and communication they provide also must be fully accessible.<sup>199</sup> Moreover, the CRPD Committee has specifically required States Parties to provide adequate support and accommodations to persons with intellectual or psychosocial disabilities in order to ensure their ability to exercise their rights in the justice system.<sup>200</sup> The accessibility requirements in Article 9 necessarily apply to access to information in judicial proceedings, requiring that such information is available in alternative communication formats, including braille, easy to read formats, and with sign language interpretation, as needed.<sup>201</sup>

Access to information in alternative formats is important for all litigants and witnesses, including women and girls who seek redress in court for acts of violence. For instance, in *R. v. D.A.I.*, the Supreme Court of Canada reversed a lower court decision that had denied a woman with an intellectual disability the right to present evidence in court against her mother's partner who had repeatedly sexually assaulted her during the four years that he had lived in the home.<sup>202</sup> The Supreme Court held that the woman should be permitted to testify as a witness, and should receive necessary accommodations, so long as she "can communicate the evidence" and "promises to tell the truth."<sup>203</sup> The Court wrote, "[t]he underlying policy concerns—bringing the abusers to justice, ensuring fair trials and preventing wrongful conviction—also support allowing adults

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including information and communications technologies and systems, and to other facilities and services open or provided to the public).

199 CRPD Comm., *General Comment No. 2: Article 9: Accessibility*, ¶ 37, U.N. Doc. CRPD/C/GC/2 (May 22, 2014).

200 CRPD Comm., *Marlon James Noble v. Australia*, Communication No. 7/2012, ¶¶ 8(2), 9(b)(ii), U.N. Doc. CRPD/C/16/D/7/2012 (Oct. 10, 2016) (considering discriminatory the Mentally Impaired Defendants Act because it applies only to persons with cognitive impairment, and provides for their indefinite detention without any finding of guilt when they are charged with criminal offences, while persons without cognitive impairments are protected from such treatment through rules of due process and fair trial).

201 CRPD, *supra* note 8, art. 21(3); *see also id.*, art. 13 (requiring that States Parties "ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages").

202 *R. v. D.A.I.*, [2012] S.C.R. 149, 153 (Can.).

203 *Id.* at 150, 165.



with mental disabilities to testify.”<sup>204</sup> Thus, this Court recognized that States Parties have an obligation to ensure not only that evidentiary rules, investigations, and other procedures are followed, but also that women and girls with disabilities receive the support they may need to pursue their rights and remedies under law.<sup>205</sup>

## V. Regional Human Rights Legal Protections For Women And Girls With Disabilities Who Experience Violence

In addition to international legal protections under the CEDAW, CRC, and CRPD, as discussed above, regional human rights treaties afford additional protections for women and girls with disabilities who experience violence. This section discusses regional legislative and judicial initiatives to address the problem of violence against women and girls with disabilities.

### A. *The Inter-American Regional System of Human Rights*

The Inter-American Convention on the Prevention, Punishment and Eradication of Violence against Women (“Convention of Belém do Pará”)<sup>206</sup> protects the right of women to be free from violence in the public and private spheres.<sup>207</sup> It also calls on States Parties to take into account the special vulnerability of women with disabilities.<sup>208</sup> Moreover, Article 7 of the Convention urges States Parties to exercise due diligence to prevent, investigate and punish acts of violence against women, regardless of whether such acts are perpetrated by the State or by private persons.<sup>209</sup> As such, States Parties can be held responsible under this provision not only for committing violence against women but also for failing to “apply due diligence to prevent, investigate and impose penalties for violence against women.”<sup>210</sup> In addition, Article 7(e) also holds States Parties accountable for failing to prevent violence and for

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204 *Id.* at 151.

205 *Cf.*, SISTERS OF FRIDA & STAY SAFE EAST, JOINT DPO SUBMISSION ON DISABLED WOMEN FOR THE HUMAN RIGHTS COMMITTEE’S REVIEW OF THE UNITED KINGDOM (2015).

206 Organization of American States, Inter-American Convention on the Prevention, Punishment and Eradication of Violence Against Women, June 9, 1994, O.A.S.T.S. No. A-61 [hereinafter Convention of Belém do Pará].

207 Convention of Belém do Pará, *supra* note 206, art. 3.

208 *Id.* art. 9.

209 *Id.* art. 7(a)–(b).

210 *Id.* art. 7(b).

not enacting appropriate legislation prohibiting such violence.<sup>211</sup> Further, Article 7(g) requires States Parties to establish fair and effective legal procedures for women who have been subjected to violence, including adopting protective measures, the right to a timely hearing, and effective access to restitution and reparations.<sup>212</sup>

According to Article 8(a) of the Convention of Belém do Pará, States Parties are also required to promote social awareness to end violence against women.<sup>213</sup> Article 8(b) also requires States Parties to design and implement educational programs that seek to change cultural patterns and attitudes that give rise to violence.<sup>214</sup> In addition, Article 8(c) requires training programs on prevention, punishment, and eradication of violence against women, for police, law enforcement, and other personnel in the justice system.<sup>215</sup> Article 8(d) also requires States Parties to provide specialized services for women who have been subjected to violence, including shelters and counseling.<sup>216</sup>

In addition to the Convention itself, the Inter-American Commission on Human Rights (IACHR) as well as the Inter-American Court on Human Rights have recently decided several cases that further clarify States Parties' obligations to women subjected to violence, including women with disabilities. For example, in *Maria Da Penha Maia Fernandes v. Brazil*, the Commission found that Brazil's failure to prosecute the husband of Maria Da Penha for attempted murder constituted a pattern of State-condoned violence against women.<sup>217</sup> After Maria Da Penha became disabled as a result of her husband's attacks, the Commission concluded that Brazil had violated her rights "and failed to carry out its duty assumed under Article 7 of the Convention of Belém do Pará and Articles 8 and 25 of the American Convention; both in relation to Article 1(1) of the Convention, as a result of its own failure to act and tolerance of the violence inflicted."<sup>218</sup> Accordingly, the Commission recommended that Brazil complete criminal proceedings against the husband, conduct an exhaustive investigation to determine

211 *Id.* art. 7(e).

212 *Id.* art. 7(g).

213 *Id.* art. 8(a).

214 *Id.* art. 8(b).

215 *Id.* art. 8(c).

216 *Id.* art. 8(d).

217 *Fernandes v. Brazil (Maria Da Penha)*, Case 12.051, Inter-Am. Comm'n H.R., Report No. 54/01, OEA/Ser.L./III.111, doc. 20 ¶¶ 2, 55 (2000).

218 *Id.* ¶ 60.4.

responsibility for the delays that prevented an effective prosecution of the perpetrator, and provide compensation to Maria de Penha, as well as implementation of domestic violence awareness trainings and the development of new procedural mechanisms for victims of domestic violence in Brazil.<sup>219</sup>

In another case, *González et al. ("Cotton Field") v. Mexico*, the Inter-American Court of Human Rights found Mexico responsible for failing to effectively investigate, prosecute, and prevent the murders of three young women, who had been reported as missing, and whose bodies were found in a cotton field, with signs of sexual violence and other forms of physical abuse.<sup>220</sup> The Court held the state of Mexico responsible for the violation of the right to life, integrity, and personal freedom of these young women and required the State to adopt domestic regulations implementing the requirements of Convention of the Belém do Pará as well as the Inter-American Convention.<sup>221</sup> In so doing, the Court cited a case involving residents of a state institution, *Ximenes-Lopes*.<sup>222</sup> The Court reasoned that just as the State had failed to protect persons with mental disabilities who were in custody or care of the State in an institution in the case of *Ximenes-Lopes*, the State had failed to comply with its obligations to the women in the *Cotton Field* case.<sup>223</sup> The specific obligations that the State had failed to provide were, according to the court, to provide "care and prevent the breach of the right to life and humane treatment, as well as . . . its duty to regulate and monitor health care services, which are special duties derived from its obligation to guarantee the rights enshrined in Articles 4 and 5 of the American Convention."<sup>224</sup> Similarly, in the case of *Yakye Axa*, which dealt with an indigenous community who had been displaced and were temporarily living in poverty-stricken conditions in an area alongside

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219 *Id.* ¶¶ 61.1–61.4.

220 *Gonzalez et al. ("Cotton Field") v. Mexico*, Merits, Reparations, and Costs, Judgment, Inter-Am. Ct. H.R. (ser. C) No. 205, ¶ 602 (Nov. 16, 2009).

221 *Id.*

222 *Id.* ¶ 4 (Garcia-Sayan, J., concurring) (citing *Ximenes-Lopes v. Brazil*, Merits, Reparations, and Costs, Judgment, Inter-Am. Ct. H.R. (ser. C) No. 149, ¶ 146 (July 4, 2006)).

223 *Id.* ¶¶ 3, 4 (Garcia-Sayan, J., concurring) (citing *Ximenes-Lopes v. Brazil*, Merits, Reparations, and Costs, Judgment, Inter-Am. Ct. H.R. (ser. C) No. 149, ¶ 146 (July 4, 2006)).

224 *Id.* ¶ 4 (Garcia-Sayan, J., concurring) (citing *Ximenes-Lopes v. Brazil*, Merits, Reparations, and Costs, Judgment, Inter-Am. Ct. H.R. (ser. C) No. 149, ¶ 146 (July 4, 2006)).

the highway, the Court held that the State had failed to exercise its “duty to take positive, concrete measures geared toward fulfillment of the right to a decent life.”<sup>225</sup> Moreover, in the *Cotton Field* case, the Court ordered the State to compensate the family of the victims, and to punish the perpetrators. The Court also ordered the State to erect a monument in memory of the victims, standardize protocols and services to provide justice to victims based on international standards, and to address harmful stereotypes about women by conducting training programs on human rights and gender for civil servants.<sup>226</sup>

In addition to this Convention, the Inter-American system also has adopted the Inter-American Convention for the Elimination of All Forms of Discriminations against Persons with Disabilities (CIADDIS).<sup>227</sup> The CIADDIS applies specifically to the rights of people with disabilities to access justice and calls upon States Parties to adopt legislative, social, and educational measures to eliminate discrimination against persons with disabilities, including ensuring the availability of goods, services, facilities, as well as employment, transportation, communications, housing, education, and administration of justice for people with disabilities.<sup>228</sup>

Recently, in *Chinchilla Sandoval v. Guatemala*, the Inter-American Court of Human Rights was asked to apply the CIADDIS to a case involving claims against the state for breach of its obligation to protect the rights of women with disabilities to personal integrity, life, judicial guarantees, and judicial protection.<sup>229</sup> In this 2016 case, a woman with disabilities (diabetes and a motor and vision disability) died in prison as the result of a fall.<sup>230</sup> The Court held the State responsible for her death due to its failure to ensure her safety and for failing to provide her reasonable accommodations.<sup>231</sup>

225 *Id.* ¶ 4 (Garcia-Sayan, J., concurring) (citing *Yakye Axa Indigenous Community v. Paraguay*, Merits, Reparations, and Costs, Judgment, Inter-Am. Ct. H.R. (ser. C) No. 125, ¶ 162 (June 17, 2005)).

226 *Gonzalez et al. (“Cotton Field”) v. Mexico*, Merits, Reparations, and Costs, Judgment, Inter-Am. Ct. H.R. (ser. C) No. 205, ¶ 602 (Nov. 16, 2009).

227 Organization of American States, Inter-American Convention for the Elimination of All Forms of Discrimination Against Persons with Disabilities, June 7, 1999, AG/RES. 1608 (XXIX-0/99), <http://www.oas.org/juridico/english/ga-res99/eres1608.htm>.

228 *Id.* art. III, § 1(a).

229 *See Chinchilla Sandoval v. Guatemala*, Merits, Reparations, and Costs, Judgment, Inter-Am. Ct. H.R. (ser. C) No. 312, ¶¶ 207, 327 (Feb. 29, 2016).

230 *Id.*

231 *Id.* ¶¶ 215–19.

In addition to these cases involving the rights of women with disabilities to be free from violence, the IACHR has held hearings regarding the situation of legal capacity and access to justice of men and women with disabilities, generally, in Latin America. At these hearings, the IACHR has accepted testimony of organizations about the many challenges women with disabilities who are subjected to violence face in accessing justice and other assistance from the State.<sup>232</sup> For example, Disability Rights International and partner organizations challenged the Mexican government at a 2012 hearing by presenting evidence of torture in psychiatric institutions, orphanages, and other social care facilities.<sup>233</sup> Similarly, the Commission held another hearing in 2014, titled, “Situation of Legal Standing and Access to Justice for Persons with Disabilities in Latin America,” which was the first thematic hearing in the region related to the rights of persons with disabilities.<sup>234</sup>

### **B. The African Regional System of Human Rights**

Article 8 of the Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Women in Africa (The Maputo Protocol) protects the rights of women to access justice and equal protection under law. Among other protections, it ensures their right to access judicial and legal services as well as requiring reform of discriminatory laws and practices.<sup>235</sup> Article 23 of the Maputo Protocol provides additional protections for women with disabilities to be free of violence, and calls upon States to take measures to facilitate their access to employment, professional training, and participation in decision-making, commensurate with their physical, economic, and social needs.<sup>236</sup>

The first (and only case to date) that the African Commission on Human Rights has decided involving the rights of people with

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232 To review the list of hearings, see *Rights of Persons with Disabilities*, OAS, <http://www.oas.org/es/cidh/audiencias/TopicsList.aspx?Lang=en&Topic=44> (last visited July 24, 2018).

233 *Complaints of Institutional Segregation and the Abuse of Children and Adults with Disabilities in Mexico*, ORG. OF AM. STATES (Mar. 23, 2012) <http://www.oas.org/es/cidh/audiencias/TopicsList.aspx?Lang=en&Topic=44>.

234 Inter-Am. Comm’n H.R., *Situation of Legal Standing and Access to Justice for Persons with Disabilities in Latin America*, ORG. OF AM. STATES (Mar. 25, 2014), <http://www.oas.org/es/cidh/audiencias/TopicsList.aspx?Lang=en&Topic=44>.

235 Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Women in Africa, art. 8, CAB/LEG/66.6 (Sept. 13, 2000).

236 *Id.* art. 23.

disabilities is the case of *Purohit and Another v. The Gambia*.<sup>237</sup> In this case, the Court held that Gambia had violated the rights of people with mental disabilities detained in an institution, including the denial of their legal capacity based on their disability, in violation of the African Charter on Human and Peoples' Rights.<sup>238</sup>

However, the first case decided by the African Commission involving women's rights, specifically, is the case of *EIPR and Interights v. Egypt*.<sup>239</sup> In this case, the Commission found that Egypt had failed to protect four women journalists from violence, thereby violating their rights to equality and non-discrimination, dignity, and protection from cruel, inhuman, and degrading treatment, as well as their right to free expression, among others, in violation of the African Charter on Human and Peoples' Rights.<sup>240</sup> This decision recognizes the sexual harassment and violence suffered by women in public places because of gender-based discrimination and gender stereotypes.<sup>241</sup> As more and more countries in the region continue to ratify the CRPD and work to conform their laws to the CRPD, women with disabilities may, hopefully, have greater access to protections from violence and to ensure their right to legal capacity and access to justice.

### C. *The European Regional System of Human Rights*

In 2011, the Council of Europe adopted the Convention on Preventing and Combating Violence against Women and Domestic Violence.<sup>242</sup> This Convention, known as the Istanbul Convention, recognizes the right of all women to live free from violence in both the public and the private spheres and that this right shall be secured without discrimination on any ground, including disability.<sup>243</sup> The

237 See generally *Purohit and Another v. The Gambia*, Communication 241/01, African Commission on Human and Peoples' Rights [Afr. Comm'n H.P.R.] (May 29, 2003); see also *African Commission Adopts Draft Protocol on Persons with Disabilities' Rights*, INT'L. JUST. RESOURCE CTR. (Apr. 20, 2016), <http://www.ijrcenter.org/2016/04/20/african-commission-adopts-draft-protocol-on-persons-with-disabilities-rights/>.

238 *Purohit*, Communication 241/01, Afr. Comm'n H.P.R. 1–3, 73–75.

239 *Interights & the Egyptian Initiative for Personal Rights v. Egypt*, Communication 323/06, Afr. Comm'n H.P.R. (Dec. 16, 2011).

240 *Id.* ¶ 275(i).

241 *Id.* ¶ 166.

242 Council of Europe, Convention on Preventing and Combating Violence Against Women and Domestic Violence, May 11, 2011, C.E.T.S 210 [hereinafter Istanbul Convention].

243 *Id.* art. 4.



Convention also calls upon States Parties to specifically refrain from engaging in acts of violence against women and ensures that State authorities, and other actors acting on the State's behalf, act in conformity with this obligation, as well as take the necessary legislative and other measures to exercise due diligence to prevent, investigate, punish, and provide reparation for acts of violence perpetrated by non-State actors.<sup>244</sup>

The Istanbul Convention also requires States Parties to prevent violence against women by developing programs related to awareness-raising, education, participation of the private sector and the media, as well as training of professionals for avoiding secondary victimization and providing appropriate referrals in cases.<sup>245</sup> In addition, the Istanbul Convention requires States Parties to ensure effective cooperation in protecting and supporting victims and witnesses of violence between relevant state agencies, including the judiciary, prosecutors, law enforcement agencies, local and regional authorities as well as non-governmental organizations.<sup>246</sup>

Like the Inter-American and African regional human rights courts and commissions, the European Court and Commission of Human Rights have heard cases involving the application of EU treaties to violence against women, including women with disabilities. For example, in *X and Y v. the Netherlands*, a girl with a mental disability (Y) and her father (X) brought a case against the Netherlands regarding her rape in an institution by the relative of the supervisor of the institution.<sup>247</sup> The rape occurred on the day after Y's sixteenth birthday.<sup>248</sup> The age of consent for sexual relationships in the Netherlands at that time was 16.<sup>249</sup> Since the young woman was of the age of consent, but lacked legal capacity, she could not sign a complaint; instead, her father (X) signed for her.<sup>250</sup> However, since the law requires that victims of consenting age must sign the complaint themselves, the prosecutor agreed not to bring charges against the perpetrator, so long as certain conditions were met.<sup>251</sup> The European Court of Human Rights found that the State had violated

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244 *Id.* art. 5.

245 *Id.* art. 12–17.

246 *Id.* art. 18.

247 *X and Y v. the Netherlands*, App. No. 8978/80, Eur. Ct. H.R., ¶¶ 1, 7–8 (1985).

248 *Id.*

249 *Id.* ¶ 15.

250 *Id.* ¶ 9.

251 *Id.*



the rights of the young woman by failing to charge the perpetrator.<sup>252</sup> In particular, the Court found that the State denied the young woman her right to respect private and family life under Article 8 of the European Convention on Human Rights, which requires States Parties to protect individuals against arbitrary interference by the public authorities.<sup>253</sup> In this case, the Court found that the Dutch Criminal Code presented a gap in the law with respect to people with mental disabilities (as well as minors) since it did not provide the complainant with effective protection under Article 8 of the Convention.<sup>254</sup>

In another case, *Mikhaylenko v. Ucraina*, the European Court of Human Rights found that Mikhaylenko had been denied her right of access to justice because authorities denied her the right to challenge her guardianship order.<sup>255</sup> Mikhaylenko had sought to end her guardianship, which had been ordered based on a diagnosis of paranoid schizophrenia.<sup>256</sup> When she went to court to challenge the guardianship she was not even permitted to participate in the proceedings.<sup>257</sup> The court refused to accept her complaint because, as a woman under guardianship, she was considered by the court to lack the requisite legal capacity under law to pursue the action.<sup>258</sup> Such challenges to guardianship under Article 12 of the CRPD have been brought, and won, in other jurisdictions.<sup>259</sup>

## VI. Violence Against Women with Disabilities in Peru: a Case Study

Unless and until a country conforms their domestic laws to a treaty it has ratified, the treaty will have little, if any, effect on changing state practices. With respect to the CRPD, States Parties have begun to develop domestic laws to conform to the treaty. Peru is an example of a country that is working to develop domestic laws to conform to the CRPD.<sup>260</sup> Although the domestic legal reform

252 *Id.* ¶¶ 28–30.

253 *Id.* ¶¶ 21–23.

254 *Id.* ¶ 30.

255 *Mikhaylenko v. Ucraina*, App. No. 49069/11, Eur. Ct. H.R., ¶ 40 (2013).

256 *Id.* at 33.

257 *Id.* at 37.

258 *Id.* at 40.

259 *See, e.g.,* KANTER, *supra* note 8, at 246–51, 266–78; *see also* Kanter & Tolub, *supra* note 86, at 582–88.

260 Constitución Política del Perú [Peruvian Constitution], art. 55, IV Final and Transitory Provision; Código Procesal Constitucional del Perú [Peruvian

has begun, all of Peru's laws do not currently comply fully with the CRPD.

In 2008, Peru was one of the first countries to ratify the CRPD.<sup>261</sup> Since then, it has been working to conform its domestic laws to the CRPD.<sup>262</sup> To further this goal, Peru adopted the "General Law on Persons with Disabilities" (Act 29973) in 2012, and its implementing regulations, in 2014.<sup>263</sup> This law improves upon Peru's prior disability law by adopting the social model of disability. The new law strives to "establish the legal framework for the promotion, protection and fulfillment of the rights of persons with disabilities, on an equal basis with others, by promoting their development and full and effective inclusion in political, social, economic, cultural and technological life."<sup>264</sup> Also, this law includes a definition of persons with disabilities and principles in line with the CRPD,<sup>265</sup> such as: the denial of reasonable accommodation as discrimination on the basis of disability,<sup>266</sup> the equal recognition before law of all persons with disabilities,<sup>267</sup> the right to live independently and be included in the

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Procedural Constitutional Code], art. V. As a monist country, the ratified treaties entered into force and became part of Peru's national legislation.

261 The CRPD and its Optional Protocol were signed by Peru on March 30, 2007 and ratified on January 30, 2008 (entered into force on May 3, 2008). See *Convention on the Rights of Persons with Disabilities* (CRPD), UNITED NATIONS, <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> (last visited July 24, 2018).

262 Arlene S. Kanter, *The Globalization of Disability Rights Law*, 30 SYRACUSE J. INT'L L. & COM. 241 (2003); see also KANTER, *supra* note 8, at 291–305 (upon ratification, States Parties may choose to conform their domestic laws to the terms of the treaty). See also INT'L DISABILITY ALL., REPORT ON THE FOLLOW-UP IDA MISSION IN PERU 12–13 (2017), <http://www.internationaldisabilityalliance.org/ida-follow-up-peru-oct2015>.

263 Ley General de la Persona con Discapacidad (Ley No. 29973) [The General Law on Persons with Disabilities (Act No. 29973)] (2012) (Peru) was enacted as a result of efforts by disabled people's organizations and other civil society organizations. An English translation of the Act No. 29973 can be found at <http://www.internationaldisabilityalliance.org/resources/peru-general-law-persons-disabilities-law-no-29973> (last visited Dec. 18, 2017). The Executive adopted its implementing regulations through Supreme Decree No. 002-2014-MIMP (Apr. 8, 2014), <https://www.conadisperu.gob.pe/institucional/marco-legal>.

264 The General Law on Persons with Disabilities, *supra* note 263, art. 1.

265 *Id.* arts. 2, 3.2, 4.

266 *Id.* art. 8(2).

267 *Id.* art. 9.

community,<sup>268</sup> and the right to accessibility,<sup>269</sup> among other relevant provisions.

Peru's obligations to eliminate violence against women are also included in the Convention of Belém do Pará, mentioned above, which Peru ratified in 1996. In this framework, Peru enacted a new law in 2015, entitled the Act on the Prevention, Punishment and Eradication of Violence Against Women and Family Members.<sup>270</sup> This law addresses the special vulnerability of women with disabilities who are subjected to violence,<sup>271</sup> as well as recognizes disability as a factor in intersectional discrimination, adopting the intersectionality and gender approach.<sup>272</sup> Further, disability is recognized as a factor of vulnerability for evaluating risks of violence.<sup>273</sup> Moreover, this law recognizes domestic violence, violence in the community, and violence perpetrated or condoned by the State, as well as physical, psychological, sexual, and economic violence.<sup>274</sup> In addition, the law requires the application of the due diligence standard in cases involving violence.<sup>275</sup> In this context, the law establishes an expedited procedure for dealing with cases of violence in which the Family Courts are competent to issue protection orders.<sup>276</sup>

A study prepared by the Peruvian Ombudsman Office on the implementation of this law reports various obstacles faced by women who experience violence. These obstacles include inadequate access to justice, including the lack of effective protection orders, delays in the proceedings, stereotypes of the professionals in the justice

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268 *Id.* art. 11.

269 *Id.* art. 15.

270 Ley para Prevenir, Sancionar y Erradicar la Violencia contra las Mujeres y los Integrantes del Grupo Familiar (Ley No. 30364) [Act on the Prevention, Punishment and Eradication of Violence Against Women and Family Members (Act No. 30364)] (2015) (Peru), <https://www.mimp.gob.pe/files/transparencia/ley-30364.pdf>. The Executive adopted its implementing regulations through Supreme Decree No. 009-2016-MIMP (July 27, 2016), <https://www.gob.pe/institucion/mimp/normas-legales/20809-009-2016-mimp>

271 *Id.* arts. 1, 41.

272 *Id.* art. 3.

273 Implementing Regulations of the Act No. 30364, Supreme Decree No. 009-2016-MIMP (July 27, 2016).

274 Act on the Prevention, Punishment and Eradication of Violence Against Women and Family Members, *supra* note 270, arts. 5, 8 (Peru).

275 *Id.* art. 2.3.

276 *Id.* arts. 14–20.

sector, and lack of adequate budget allocation, among others.<sup>277</sup> Likewise, the report states that 75% of victims do not know about the Act No. 30364,<sup>278</sup> and 59% of victims find that police stations do not have adequate resources to receive their complaints.<sup>279</sup> Further, 50% of victims interviewed noted that their testimony or behavior was challenged during investigations.<sup>280</sup> This lack of credibility of testimony is even higher for women with intellectual and psychosocial disabilities, due to the denial of their legal capacity under the Civil Code.<sup>281</sup> The study also found that 14.5% of the police officers who were interviewed reported they could not communicate with women with disabilities who sought to report assaults.<sup>282</sup> Furthermore, the report states that protection orders were issued only in 42% of all such cases.<sup>283</sup>

In addition, Peru has enacted the National Plan against Gender-Based Violence 2016–2021, which recognizes violence against women with disabilities as multiple discrimination,<sup>284</sup> adopting an intersectionality and gender approach.<sup>285</sup> In particular, this plan proposes the change of sociocultural patterns that reproduce unequal power relations, and guarantees integral services to protect and rehabilitate women who are victims of violence, as well as imposes sanctions and re-education programs for aggressors.<sup>286</sup> The plan also calls for capacity-building of all involved actors.<sup>287</sup> Further, the plan establishes a data system concerning victims of violence, including their sex, age, sexual orientation, and disability condition, as well as a monitoring system with measurable indicators.<sup>288</sup>

Thus, Peru, like other countries that have ratified the CRPD,

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277 Defensoría del Pueblo de Perú [Peruvian Ombudsman Office], *La Administración de Justicia y la Visión de las Víctimas (Ley No. 30364)* [The Justice Administration and the Vision of the Victims (Act. No. 30364)], 75–76 (2017).

278 *Id.* at 68.

279 *Id.* at 70, 71.

280 *Id.* at 72.

281 Código Civil Peruano [Peruvian Civil Code], arts. 43(2), 44(2)(3).

282 *The Justice Administration and the Vision of the Victims*, *supra* note 277, at 34.

283 *Id.* at 35.

284 *See Plan Nacional contra la Violencia de Género 2016–2021 [National Plan Against Gender-Based Violence 2016–2021]*, § II(1)(p) (July 26, 2016) (Peru).

285 *Id.* § II(2)(d).

286 *Id.* § II.4.

287 *Id.* § II.5(Strategic Action 2.3).

288 *Id.* § II.5(Strategic Action 2.6.2), § II.8.

is working to amend existing laws and enact new laws that seek to address acts of violence against women with (and without) disabilities. Laws alone, however, cannot end violence or eradicate discrimination against women with disabilities. Long-held cultural beliefs and norms about women with disabilities may interfere with the exercise of the rights of women with disabilities even with the best new laws. Therefore, unless women are ensured their legal capacity, they can neither prosecute claims of violence, abuse, or exploitation nor appear as witnesses in cases against perpetrators.

As in other countries, stereotypical and paternalistic views of women with disabilities remain embedded in certain Peruvian laws. For instance, the Civil Code, the Civil Procedural Code, and the new Criminal Procedural Code all continue to presume the “incapacity” of women (and men) with intellectual or psychosocial disabilities.<sup>289</sup> Even after ratifying the CRPD and adopting the new General Law on Persons with Disabilities, which recognizes the legal capacity of all people with disabilities, Peru has no system in place to support people with disabilities in making their own decisions. Thus, despite the ratification of the CRPD, which calls for legal capacity of all men and women with all types of disability as well as a new domestic law that recognizes legal capacity, women with disabilities in Peru continue to experience denial of their equal recognition under law by the presumption of their incapacity and by permitting the state to order guardianships for them under the substitution decision-making standard.<sup>290</sup>

For example, under Article 43 of the Peruvian Civil Code, “those who for whatever reason are deprived of judgement” are absolutely incapable of exercising their rights.<sup>291</sup> Similarly, Article 44 of the Civil Code stipulates that persons referred to as “mentally retarded” and “those who suffer from mental impairment that prevents them from expressing their free will” are relatively unable to exercise their rights.<sup>292</sup>

289 See, e.g., Peruvian Civil Code, *supra* note 281, arts. 43(2), 44(2)(3), 564, 565, 576, 581; Código Procesal Civil Peruano [Peruvian Civil Procedural Code], arts. 58, 207, 222; Nuevo Código Procesal Penal de Perú [New Peruvian Criminal Procedural Code], art. 94.

290 Peruvian Civil Code, *supra* note 281, arts. 43(2), 44(2)–(3), 564, 565, 576, 581. For a discussion of the substituted decision-making standard as one of the problems of guardianship laws, see KANTER, *supra* note 8, at 235–44; Kanter & Tolub, *supra* note 86, at 603.

291 Peruvian Civil Code, *supra* note 281, art. 43(2).

292 Peruvian Civil Code, *supra* note 281, art. 44(2)–(3).

As a result of these provisions, women (as well as men) with psychosocial or intellectual disabilities continue to face discrimination and are denied access to justice and effective remedies as victims of violence. To address this concern, the Bill 872/2016-CR was submitted to conform the Civil Code to Article 12 of the CRPD, thereby recognizing the legal capacity of all people with disabilities.<sup>293</sup> However, the bill is still awaiting approval by the Peruvian Parliament.

Further, the Peruvian Civil Procedural Code, which affords the right of “all persons” to participate in the judicial process, excludes women (and men) with intellectual or psychosocial disabilities.<sup>294</sup> This law provides that a party to a judicial proceeding may be one “who may enforce the rights in discussion, those unable to do it must appear through legal representative.”<sup>295</sup> Therefore, those who for whatever reason are deprived of judgment, such as “mentally retarded” and those “who suffer from mental impairment that prevents them from expressing their will unambiguously,” as well as those under formal guardianships, cannot be a party to any legal process.<sup>296</sup> Instead, they must be represented by a legal representative or guardian. Moreover, women (and men) with disabilities who are considered “incapable” of acting on their own behalf are prohibited from appearing as witnesses in judicial proceedings since they lack legal capacity.<sup>297</sup> Also disturbing is the fact that a woman (and a man) who is not under guardianship may nevertheless be barred from participating in judicial hearings if the judge finds that she is “manifestly unable” to participate in judicial proceedings.<sup>298</sup>

The new Criminal Procedural Code further discriminates against women (and men) with disabilities by establishing that

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293 Proyecto de Ley que Modifica el Código Civil, el Código Procesal Civil y la Ley de Notariado en lo Referido al Ejercicio de la Capacidad Jurídica de las Personas con Discapacidad, Proyecto de Ley No. 872/2016-CR [Bill Amending the Civil Code, the Civil Procedural Code and the Notary Act in Relation to the Exercise of Legal Capacity of Persons with Disabilities, Bill No. 872/2016-CR] (Jan. 12, 2017), <http://www.congreso.gob.pe/pley-2016-2021>. This draft was prepared with the support of a coalition of political parties and civil society organizations. Previously, the Bill No. 4601/2014-CR was submitted but dismissed by the Parliament.

294 Peruvian Civil Procedural Code, *supra* note 289, arts. 57–58.

295 *Id.* art. 58.

296 Peruvian Civil Code, *supra* note 281, arts. 43(2), 44(2)–(3), 564, 565, 576, 581; Peruvian Civil Procedural Code, *supra* note 289, art. 58.

297 Peruvian Civil Procedural Code, *supra* note 289, arts. 222, 229.

298 *Id.* art. 207.



“those victims who are ‘unable,’” will be represented by the person designed by law,”<sup>299</sup> and that “persons who are incompetent for natural reasons cannot testify in criminal proceedings.”<sup>300</sup> Yet nowhere in the law are these terms defined. Moreover, based on long-held cultural beliefs about women with intellectual and psychosocial disabilities, women with these particular disabilities are routinely denied access to justice. In fact, all of these discriminatory provisions in Peruvian law, which are found in the laws of many other countries as well, deny women with psychosocial or intellectual disabilities access to justice by presuming their legal incapacity and denying them the opportunity to exercise one of the most basic of human rights, the right to participate in judicial proceedings. For women who are victims of violence, the effect of such laws can be devastating, since they are not only victimized by their perpetrators, but then they are victimized again by a judicial system that denies them access to justice.

In response to this situation, in 2010, Peru adopted a document, known as the *Brasilia Rules for Access to Justice for Vulnerable Persons*.<sup>301</sup> This document provides the basis for the National Plan for Access to Justice for People in Vulnerable Situation 2016–2021, which is monitored by the Judiciary. The National Plan is a progressive document that seeks to promote the protection of the rights of persons with disabilities and the rights of women who experience violence, among other vulnerable groups. On one hand, the Plan aims to ensure accessibility, implement supports, and call for the reform of the Civil Code according to the Article 12 of the CRPD.<sup>302</sup> On the other hand, the Plan seeks to promote effective protection orders and expedite procedures, provide training for judges on gender-based violence, and elaborate a protocol for these cases.<sup>303</sup> Despite its laudable goal of ensuring legal capacity, the Plan continues to discriminate against persons with disabilities by authorizing

299 New Peruvian Criminal Procedural Code, *supra* note 289, art. 94.

300 *Id.* art. 162.1.

301 *Brasilia Rules for Access to Justice for Vulnerable Persons* 6, 7 (2008), <https://www.osce.org/odihr/68082?download=true>.

302 Poder Judicial del Perú, *Plan Nacional de Acceso a la Justicia para las Personas en Situación de Vulnerabilidad 2016–2021* [National Plan for Access to Justice for People in Vulnerable Situation 2016–2021], 90–93 (2016), <https://www.pj.gob.pe/wps/wcm/connect/64ff88804d7e0bfaa85cfb2d8cfcf5ea/PLAN+NACIONAL+FINAL+22+marzo.pdf?MOD=AJPERES&CACHEID=64ff88804d7e0bfaa85cfb2d8cfcf5ea>.

303 *Id.* at 106–12.



guardianships. As the Plan states, “persons with disabilities who are absolutely incapable because they are deprived of judgement, those who are relatively incapable as the mentally retarded, and those who suffer from mental deterioration that prevent them from expressing their free will may be subject to guardianship.”<sup>304</sup> As such, the Plan is incompatible with Articles 12 and 13 of the CRPD, as discussed above.

In 2010, Peru submitted its country report to the CRPD Committee. Two years later, in 2012, the CRPD Committee issued its concluding observations, which urges Peru to adopt effective measures to prevent and redress violence against women and girls with disabilities and discusses Peru’s lack of compliance with Articles 12 and 13 of the CRPD.<sup>305</sup> In response to the CRPD Committee’s concluding observations, in 2014, the Judiciary published an administrative directive limiting the use of guardianships and the role of guardians, as a call to judges to ensure legal capacity of persons with disabilities and to establish supported decision-making systems.<sup>306</sup> As a result of this directive, judges in some jurisdictions have begun to issue decisions limiting guardianships.

For example, in 2015, Judge Béjar, the first blind judge in Peru,<sup>307</sup> held that under the CRPD and the Peruvian Constitution, the right of a person to a pension cannot be restricted based on his/her disability, and that a provision requiring guardianship in order to provide a pension was not applicable.<sup>308</sup> Based on this ruling, Judge Béjar upheld full recognition of legal capacity for Wilbert and Ruben

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304 *Id.* at 39–40.

305 *Concluding Observations Peru*, *supra* note 182, ¶¶ 15, 25. *See also* CRPD Comm., *List of Issues Prior to Reporting*, ¶¶ 7, 11, 12, U.N. Doc. CRPD/C/PER/QPR/2-3 (May 8, 2017) (asking for policies against gender-based violence, measures to repeal the restriction of legal capacity, and the progress on accessibility for access to justice).

306 Resolución Administrativa de la Presidencia del Poder Judicial [R.A.] [Administrative Resolution of the Presidency of the Judiciary] No. 272-2014-P-PJ (Sept. 4, 2014) (Peru).

307 Edwin Béjar was designated judge by Resolución Administrativa [Administrative Resolution] No 1497-2010. *See Primer juez invidente del Perú asume funciones hoy en Juzgado de Calca* [First blind judge in Peru starts functions today in Calca Court], PODER JUDICIAL DE PERU, [https://www.pj.gob.pe/wps/wcm/connect/cortesuperiorcuscopj/s\\_csj\\_cusco\\_nuevo/as\\_inicio/as\\_imagen\\_prensa/as\\_noticias/csju\\_n\\_primer\\_juez\\_invidente\\_25102010](https://www.pj.gob.pe/wps/wcm/connect/cortesuperiorcuscopj/s_csj_cusco_nuevo/as_inicio/as_imagen_prensa/as_noticias/csju_n_primer_juez_invidente_25102010).

308 Tercer Juzgado de Familia de Cusco [TJFC] [Third Family Court of Cusco], June 15, 2015, Judicial File No. 01305-2012-0-1001-JR-FC-03, 46 (Peru) (regarding guardianship).

Velasquez Ciprian, and with their approval, issued an order for them to receive support, subject to review every six months.<sup>309</sup> This decision also made history as the first decision of a Peruvian court to be published in “plain language,” in order to ensure its access to persons with intellectual disabilities and other reading challenges.<sup>310</sup> Since Judge Béjar’s decision, other Peruvian courts have issued similar decisions concerning access to social welfare benefits as well as the administration of property and inheritance for people who were considered, in the past, lacking legal capacity.<sup>311</sup>

Moreover, the Family Court authority in the Province of Santa, Peru adopted a decision in 2016, requiring all judges to apply the CRPD to their decisions and to order support, as needed, rather than guardianships.<sup>312</sup> This decision states specifically that certain articles of the Civil Code are incompatible with the CRPD.<sup>313</sup> This decision also recognizes the legal capacity of persons with disabilities and their right to support, which must be reviewed and modified, whenever necessary or requested. Finally, the decision requires judges of the family court to ensure that all persons participating in the judicial process have full access and reasonable accommodations, when needed.<sup>314</sup>

Most recently, in 2018, the Judiciary approved the “Protocol of Judicial Attention for people with disabilities.”<sup>315</sup> This Protocol

309 *Id.* at 46–48 (recognizing legal capacity of people with disabilities and supports).

310 *Id.* at 47.

311 Corte Superior de Justicia de Lima [C.S.J.L.] [Superior Court of Justice of Lima], Segundo Juzgado Constitucional de Lima [S.J.C.L.], Judicial File No. 25158-2013-0-1801-JR-CI-02 (Aug. 26, 2014) (Peru) (recognizing legal capacity of people with disabilities and supports). *See also* REPORT ON THE FOLLOW-UP IDA MISSION IN PERU, *supra* note 262, at 19 n.51 (citing Superior Court of Cusco, Case of Erika Fernandez Asin and Case of Marcos Esteban Portugal Dueñas (Jan. 2016); Teresa Lazo Echari (Apr. 2016) (providing access to social security benefits to a person with low vision)).

312 Corte Superior de Justicia del Santa [C.S.J.S.] [Superior Court of Justice of Santa], Pleno Jurisdiccional Distrital de Familia del Santa [Family Jurisdictional District Plenary], July 15, 2016, at 1, 2, 7 (on guardianship and the rights of persons with disabilities to equal recognition of legal capacity).

313 *Id.* (Court calls on judges to declare inapplicable articles 43.2, 44.2, and 44.3 of the Peruvian Civil Code for ensuring constitutionality).

314 *Id.* at 2 (providing the rules on guardianship and the rights of persons with disabilities to equal recognition of legal capacity).

315 PODER JUDICIAL DEL PERÚ [P.J.P.] [Peruvian Judiciary], PROTOCOLO DE ATENCIÓN JUDICIAL PARA PERSONAS CON DISCAPACIDAD [Protocol of Judicial Attention for People With Disabilities], <https://www.>

recognizes the legal capacity and autonomy of all persons with disabilities, as well as seeks to ensure accessibility, reasonable accommodations, and communication access in line with the CRPD standards.<sup>316</sup> Further, the Protocol establishes guidelines for providing an adequate service according to different types of disability.<sup>317</sup>

In sum, in a country such as Peru that has ratified the CRPD, the CEDAW, and the Convention of Belém do Pará, as well as adopted new treaty-compliant domestic laws, women with disabilities who experience violence remain deprived of their right to access justice due to different obstacles, including the lack of effective protection orders, delays in the proceedings, stereotypes, and existing Peruvian laws that deprive them of legal capacity. However, the Judiciary in certain cases has responded by supporting the right to legal capacity of persons with disabilities. In this way, the experience in Peru provides an important example of the significant role the judiciary can play in ensuring the protection of rights afforded under the CRPD through its application and interpretation of domestic laws to ensure compliance with the CRPD.

## VII. Recommendations to Ensure Access to Justice for Women and Girls with Disabilities Who Experience Violence

Given the various international, regional and domestic legal protections for women and girls with disabilities, as discussed in the previous sections, the fact remains that few of these laws are fully implemented. Consequently, women and girls with disabilities continue to be subjected to violence as well as denied access to justice. This section of the article proposes specific recommendations to ensure greater access to justice for women and girls with disabilities who are subjected to violence, as part of a disability-inclusive policy.<sup>318</sup> These recommendations are based on international human rights standards and best practices.

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[pj.gob.pe/wps/wcm/connect/d3afc2004393281cb222feb286bd5fbb/protocolo+de+atención+judicial+para+las+personas+con+discapacidad.pdf?mod=ajperes&cacheid=d3afc2004393281cb222feb286bd5fbb](http://pj.gob.pe/wps/wcm/connect/d3afc2004393281cb222feb286bd5fbb/protocolo+de+atención+judicial+para+las+personas+con+discapacidad.pdf?mod=ajperes&cacheid=d3afc2004393281cb222feb286bd5fbb).

316 *Id.* at 6–9.

317 *Id.* at 9–12.

318 See Catalina Devandas (Special Rapporteur on the Rights of Persons with Disabilities), *Report of the Special Rapporteur on the Rights of Persons with Disabilities*, U.N. Doc. A/71/314 (Aug. 14, 2016), <http://www.ohchr.org/EN/Issues/Disability/SRDisabilities/Pages/Reports.aspx> (providing guidance to States on how to establish disability-inclusive policies, which should include non-discrimination, accessibility and support services requirements).

### A. *Adhere to the CRPD Committee Recommendations to States Parties*

Once a country ratifies the CRPD, the country has two years to file a report to the CRPD Committee documenting the extent of its progress implementing the articles of the CRPD.<sup>319</sup> Since the CRPD has entered into force, more than 100 countries have submitted their country reports.<sup>320</sup> In response, the CRPD Committee issues a “list of issues,” to which the State Party must respond, followed by “concluding observations,” which detail the Committee’s response to the States Parties’ country reports.<sup>321</sup> In all of the country reports that have been filed to date, the CRPD Committee has noted deficiencies with respect to full compliance with the articles of the CRPD that relate to the rights of women, generally, as well as those who experience violence.

For example, in the first concluding observation that the Committee prepared in 2011, in response to Tunisia’s country report, the Committee observed that in a country whose culture has supported discriminatory treatment of women, the State Party should:

[u]ndertake studies and research in order to identify the situation and specific requirements of women with disabilities, with a view to elaborating and adopting strategies, policies and programmes, especially in the fields of education, employment, health and social protection, to promote their autonomy and full participation in society, and to combat violence against women.<sup>322</sup>

319 U.N. Handbook for Parliamentarians, Chapter Three: Monitoring the Convention and the Optional Protocol (June 2010), <https://www.un.org/development/desa/disabilities/resources/handbook-for-parliamentarians-on-the-convention-on-the-rights-of-persons-with-disabilities/chapter-three-monitoring-the-convention-and-the-optional-protocol.html>.

320 See *State Party’s Reports*, U.N. OFFICE OF THE HIGH COMM’R FOR HUMAN RIGHTS, [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=29](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4&DocTypeID=29) (last visited Apr. 23, 2018).

321 See *Concluding Observations*, CRPD, UNITED NATIONS OFFICE OF THE HIGH COMMISS’R FOR HUMAN RIGHTS, [https://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/TBSearch.aspx?TreatyID=3&DocTypeID=5](https://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?TreatyID=3&DocTypeID=5) (last visited Apr. 23, 2018).

322 CRPD Comm., *Concluding Observations of the Committee on the Rights of Persons with Disabilities, Tunisia*, ¶ 15(c), U.N. Doc. CRPD/C/TUN/CO/1 (May 13,

The Committee also encouraged Tunisia “to conduct awareness campaigns and develop educational programmes on the greater vulnerability of women and girls with disabilities with respect to violence and abuse.”<sup>323</sup>

Similarly, six years later, the Committee once again reminded States Parties of their obligation to protect the rights of women to be free from violence as well as discrimination, in response to Luxembourg’s country report.<sup>324</sup> As the Committee recommended to Luxembourg, the State Party should enact “legislation, including monitoring mechanisms, to detect, prevent and combat violence within and outside the home of persons with disabilities, especially for women and children with disabilities.”<sup>325</sup> The Committee also encouraged “the State Party to expedite the ratification of the Convention on Preventing and Combating Violence against Women and Domestic Violence (Istanbul Convention).”<sup>326</sup>

In another recent concluding observation in response to the country report of the United Kingdom, the CRPD Committee required the State Party to “[e]stablish measures to ensure equal access to justice and to safeguard persons with disabilities, particularly women, children, intersex persons and elderly persons with disabilities from abuse, ill-treatment, sexual violence and exploitation.”<sup>327</sup>

Moreover, with respect to Article 16, specifically, the CRPD Committee has advised States Parties, such as Peru, to “amend its legislative framework to provide special protection to women and girls with disabilities, as well as to adopt effective measures to prevent and redress violence against women and girls with disabilities.”<sup>328</sup>

In addition to its concluding observations, in 2016, the CRPD Committee also issued *General Comment Number 3*, specifically addressing Article 6, Women with Disabilities. *General Comment*

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2011) [hereinafter Concluding Observations Tunisia].

323 *Id.* ¶ 27.

324 CRPD Comm., *Concluding Observations on the Initial Report of Luxembourg*, U.N. Doc. CRPD/C/LUX/CO/1, ¶¶ 14, 15, 32, 33. (Oct. 10, 2017, reissued Oct. 23, 2017) [hereinafter Concluding Observations Luxembourg].

325 *Id.* ¶ 33(b).

326 *Id.*

327 CRPD Comm., *Concluding Observations on the Initial Report of the United Kingdom of Great Britain and Northern Ireland*, ¶ 39(a), U.N. Doc. CRPD/C/GBR/CO/1 (Oct. 3, 2017).

328 *Concluding Observations Peru*, *supra* note 182, ¶ 15.

*Number 3* identifies violence against women and girls with disabilities as an issue of international concern and one of its main priority areas.<sup>329</sup>

The CRPD Committee has also expressed concern about the failure of domestic laws and policies on violence against women to address the situation of women and children with disabilities.<sup>330</sup> As discussed above, one of the most significant legal impediments for women with disabilities in seeking access to justice is the medical model of disability contained in most countries' domestic laws. Such laws presume the incapacity of women with intellectual or psychosocial disabilities, and authorizes guardianships for them, under a substituted decision-making model.<sup>331</sup> To fully protect women with disabilities from violence, the CRPD Committee has recognized that domestic laws must be changed to conform to Article 12 of the CRPD, which recognizes the legal capacity of all persons with disabilities, including women with disabilities who are subjected to violence. In sum, in order to guarantee the rights of women with disabilities to participate actively in judicial proceedings against their perpetrators, States Parties must adhere to the CRPD Committee's recommendations on legal capacity to ensure the ability of these women to participate fully, and with accommodations, as needed, in all aspects of judicial proceedings.<sup>332</sup>

### ***B. Mainstream Gender and Disability Policies to Ensure Access to Justice for Women with Disabilities Who Experience Violence***

In addition to recognizing legal capacity for all women with disabilities, the CRPD Committee has urged the integration of a disability-sensitive perspective in the development of educational

329 *General Comment No. 3: Article 6: Women and Girls with Disabilities*, *supra* note 7, ¶ 10.

330 See, e.g., *Concluding Observations Argentina*, *supra* note 179, ¶ 29; CRPD Comm., *Concluding Observations on the Initial Report of Azerbaijan*, ¶ 16 U.N. Doc. CRPD/C/AZE/CO/1 (May 12, 2014) [hereinafter *Concluding Observations Azerbaijan*]; *Concluding Observations Brazil*, *supra* note 69, ¶ 14; CRPD Comm., *Concluding Observations on the Initial Report of the Cook Islands*, ¶ 29, U.N. Doc. CRPD/C/COK/CO/1 (May 15, 2015) [hereinafter *Concluding Observations Cook Islands*]; *Concluding Observations Czech Republic*, *supra* note 20, ¶ 34; *Concluding Observations Peru*, *supra* note 182, ¶ 25.

331 See e.g., Peruvian Civil Code, *supra* note 281, art. 43, 44, 564.

332 See generally Agustina Palacios, *Género, discapacidad y acceso a la justicia* [Gender, disability and access to justice], in 1 DISCAPACIDAD, JUSTICIA Y ESTADO [Disability, Justice and State] (2012).



programs on preventing sexual and domestic violence.<sup>333</sup> For instance, in Uruguay, the Gender Unit of the Disability Program within the Ministry for Social Development has led an awareness raising campaign on gender and disability-based violence, which has included trainings for different offices in the government, and tracking gender and disability violence.<sup>334</sup> Similarly, the National Council for the Integration of Persons with Disabilities (CONADIS), as a focal point in Peru for monitoring the CRPD, should mainstream gender and disability in the public policy related to violence against women.<sup>335</sup>

Moreover, Handicap International (now known as Humanity and Inclusion) has sponsored a project on violence against women whose aim is to highlight violence-related programs run by and for women with disabilities.<sup>336</sup> The goal of highlighting these programs is to raise awareness internationally as well as in individual countries about the importance of mainstreaming gender and disability by including the perspective and experience of women and girls with disabilities in all violence prevention programs as well as including the issue of violence against women and girls with disabilities as a priority in all disability-related and women-related empowerment programs.

### C. *Collect Disaggregated Data*

Article 31 of the CRPD requires States Parties to collect data on their respective populations of people with disabilities. Yet little data exists on violence against women with disabilities. This lack of data contributes to the invisibility of women with disabilities who experience violence. To address this concern, the CRPD Committee has recommended the collection of disaggregated data<sup>337</sup>

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333 CRPD Comm., *Concluding Observations on the Initial Report of the Republic of Korea*, ¶ 14, U.N. Doc. CRPD/C/KOR/CO/1 (Oct. 29, 2014).

334 HANDICAP INT'L, *supra* note 46, at 26.

335 More information about the National Council for the Integration of Persons with Disabilities (CONADIS) is available at <https://www.conadisperu.gob.pe>.

336 See HANDICAP INT'L, *supra* note 46, at 4. One of the authors of this article, Arlene S. Kanter, is a member of the Technical Advisory Group (TAG) of the HI Making it Work Initiative. In 2015, the TAG identified 11 programs around the world, mostly led by women with disabilities to eradicate and address violence against girls and women with disabilities. The TAG is currently reviewing programs in the African region and will select among those several to join the project. For more information about this project, contact Arlene Kanter, at [kantera@law.sy.edu](mailto:kantera@law.sy.edu).

337 *Concluding Australia*, *supra* note 22, ¶ 54; CRPD Comm., *Concluding Observations*



on where women with disabilities live, what barriers they face, and what supports they require and that such data be disaggregated by age,<sup>338</sup> sex/gender,<sup>339</sup> disability,<sup>340</sup> place of residence,<sup>341</sup> region,<sup>342</sup> and cultural background.<sup>343</sup> Moreover, with additional data, States Parties will choose or be forced to provide additional support for disability and gender inclusive programs that prevent violence. For example, after reviewing data on women with disabilities who experience violence in Sweden, the Swedish Government completed a comprehensive study on violence against women with disabilities and has proposed strategies to end such violence.<sup>344</sup>

#### **D. Ensure Accessibility and Reasonable Accommodations in Prevention and Protection Programs**

The CRPD Committee has encouraged States Parties to adopt measures to prevent and eliminate violence against women and girls with disabilities in the community and in institutions<sup>345</sup> in ways that

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*on the Initial Report of Sweden*, ¶ 58, U.N. Doc. CRPD/C/CWE/CO/1 (May 12, 2014) [hereinafter *Concluding Observations Sweden*].

338 See, e.g., *Concluding Observations Australia*, *supra* note 19, ¶ 54; *Concluding Observations Peru*, *supra* note 182, ¶ 47; *Concluding Observations Sweden*, *supra* note 326, ¶ 56.

339 See, e.g., *Concluding Observations Australia*, *supra* note 19, ¶ 54; *Concluding Observations Azerbaijan*, *supra* note 319, ¶ 50; *Concluding Observations Peru*, *supra* note 182, ¶ 47; *Concluding Observations Sweden*, *supra* note 326, ¶ 56; *Concluding Observations Tunisia*, *supra* note 322, ¶ 37.

340 See, e.g., *Concluding Observations Australia*, *supra* note 19, ¶ 54.

341 *Id.*

342 *Concluding Observations Azerbaijan*, *supra* note 321, ¶ 50.

343 *Concluding Observations Australia*, *supra* note 19, ¶ 54.

344 SWEDISH NAT'L BD. OF HEALTH & WELFARE, *LOOKING THE OTHER WAY: A STUDY GUIDE TO FEMALE VICTIMS OF VIOLENCE WITH DISABILITIES* (2012).

345 See, e.g., CRPD Comm., *Concluding Observations on the Initial Report of Canada*, ¶ 34(a)–(c), U.N. Doc. CRPD/C/CAN/CO/1 (May 8, 2017) (Committee expresses concern about “the lack of information about measures to prevent violence against persons with disabilities in family settings and against persons living in institutions.”); CRPD Comm., *Concluding Observations on the Initial Report of Italy*, ¶ 43, U.N. Doc. CRPD/C/ITA/CO/1, ¶ 44, (Oct. 6, 2016) (Committee expresses concern “at the lack of legal provisions and monitoring mechanisms to detect, prevent and combat violence within and outside the home.”). With respect to violence against women with disabilities in institutions, in particular, the Committee has encouraged Latvia to ratify the Convention on Preventing and Combating Violence Against Women and Domestic Violence adopted by the Council of Europe. CRPD Comm., *Concluding Observations on the Initial Report of Latvia*, ¶ 11(d), U.N. Doc.

are both effective<sup>346</sup> and accessible.<sup>347</sup> In this context, the Committee has expressed concern about the inaccessibility of hotlines and shelters for women with disabilities,<sup>348</sup> as well as lack of accessible information related to protections against gender-based violence.<sup>349</sup>

With respect to protections against violence, States Parties are required to provide adequate, timely, and accessible services to victims of gender-based violence, including health care, shelter services, and reasonable accommodations and information in alternative formats.<sup>350</sup> For instance, women with disabilities may require accessible telephones and accessible SMS hotlines as well as accessible information about how to obtain and enforce orders of protection.<sup>351</sup> In addition, a safe and conducive environment at police stations and crisis centers is necessary to facilitate communication with victims of violence, including, and perhaps especially, for women and girls with disabilities. Moreover, victims of sexual violence also need access to sexual and reproductive health services, including emergency contraception and anti-retroviral medication for post HIV-exposure prophylaxis.<sup>352</sup> The Special Rapporteur on Violence

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CRPD/C/LAV/CO/1 (Oct. 10, 2017). The Committee also expressed its concern about: “(a) [t]he high number of deaths occurring in residential institutions of adults with intellectual and/or psychosocial disabilities, the lack of, first, information regarding any investigations that have been conducted to establish the cause of death and, second, prosecutions for criminal acts; (b) [a]llegations of violence and abuse, including sexual violence, of persons with disabilities living in institutions.” *Id.* ¶ 28(a)–(b).

346 See, e.g., *Concluding Observations Belgium*, *supra* note 13, ¶; *Concluding Observations Brazil*, *supra* note 69, ¶ 15; CRPD Comm., *Concluding Observations on the Initial Report of the European Union*, ¶ 45, U.N. Doc. CRPD/C/EU/CO/1 (Oct. 2, 2015); *Concluding Observations Hungary*, *supra* note 180, ¶ 32.; CRPD Comm., *Concluding Observations on the Initial Report Paraguay*, ¶ 18, U.N. Doc. CRPD/C/PRY/CO/1 (May 15, 2013); *Concluding Observations Peru*, *supra* note 182, ¶ 15; CRPD Comm., *Concluding Observations of the Committee on the Rights of Persons with Disabilities Spain*, ¶ 22, U.N. Doc. CRPD/C/ESP/CO/1 (Oct. 19, 2011).

347 See, e.g., *Concluding Observations Brazil*, *supra* note 69, ¶ 15; *Concluding Observations Kenya*, *supra* note 42, ¶ 32.

348 See, e.g., *Concluding Observations Cook Islands*, *supra* note 319, ¶ 29; CRPD Comm., *Concluding Observations on the Initial Report of the Dominican Republic*, ¶ 32, U.N. Doc. CRPD/C/DOM/CO/1 (May 8, 2015) [hereinafter *Concluding Observations Dominican Republic*]; *Concluding Observations Ukraine*, *supra* note 179, ¶ 11.

349 *Concluding Observations Dominican Republic*, *supra* note 337, ¶ 32.

350 *General Comment No. 2: Article 9: Accessibility*, *supra* note 201, ¶ 37.

351 Human Rights Watch, *Human Rights Watch Submission to the CRPD Draft General Comment on Article 6: Women with Disabilities*, ¶ 5 (2016).

352 Women Enabled Int’l, *Women Enabled International Submission to the CRPD’ Draft*

Against Women also has called for the creation of specialized investigatory and prosecutorial units for violence against women, elimination of complicated or degrading reporting procedures, and an end to practices that require the referral of victims of violence to social services rather than legal services.<sup>353</sup>

Further, the CRPD Committee has highlighted the importance of making information available to victims of violence in accessible formats,<sup>354</sup> as well as the need for sign language interpreters<sup>355</sup> and free legal aid.<sup>356</sup> These recommendations are based on research that has shown that lack of accessible information about violence against women with intellectual or psychosocial disabilities is an obstacle to ensuring their safety, especially in the context of interpersonal violence.<sup>357</sup> Research has also shown the importance of violence prevention programs, especially for women who are at risk of sexual abuse, who may not typically report such crimes.<sup>358</sup> Such programs should also include materials that are culturally appropriate.<sup>359</sup>

To further these goals, the Costa Rican Judiciary, for example, adopted a *Protocol of Attention for the Effective Access to Justice of People with Psychosocial Disabilities in Costa Rica*.<sup>360</sup> According to this Protocol,

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*General Comment on Article 6: Women with Disabilities 3* (2016).

- 353 Manjoo, *supra* note 17, ¶ 98 (b) (f); *see also*, U. N. Div. for the Advancement of Women, Rep. of the Expert Group Meeting on Good Practices in Legislation on Violence Against Women, at 16–24, 39–61 (2008).
- 354 *See, e.g., Concluding Observations El Salvador, supra* note 20, ¶¶ 29, 30; *Concluding Observations Kenya, supra* note 39, ¶ 25; *Concluding Observations Mongolia, supra* note 182, ¶ 22.
- 355 *See, e.g., Concluding Observations Kenya, supra* note 39, ¶ 25; *Concluding Observations Mongolia, supra* note 182, ¶ 22.
- 356 *See e.g., Concluding Observations Kenya, supra* note 39, ¶ 25.
- 357 Human Rights Watch, *Letter to United Nations CRPD on Half Day of General Discussion on Women and Girls with Disabilities* (Apr. 3, 2013, 5:52 PM), <http://www.hrw.org/news/2013/04/03/letter-united-nations-crpdc-half-day-general-discussion-women-and-girls-disabilities>; *see also Concluding Observations Brazil, supra* note 69, ¶ 14.
- 358 *See generally* Amy Swango-Wilson, *Meaningful Sex Education Programs for Individuals with Psychosocial/ Developmental Disabilities*, 29 *SEXUALITY & DISABILITY* 113 (2011).
- 359 Gen. Assembly of the European Disability Forum, *2nd Manifesto of The Rights of Women and Girls with Disabilities in the European Union*, §§ 5.6, 57–58 (2011), <http://www.uildm.org/wp-content/uploads/2011/11/2ndmanifestoEN.pdf>.
- 360 PODER JUDICIAL DE COSTA RICA [Judiciary of Costa Rica], *PROTOCOLO DE ATENCIÓN PARA EL EFECTIVO ACCESO A LA JUSTICIA DE PERSONAS CON DISCAPACIDAD PSICOSOCIAL* [Protocol of Attention for Effective Access to Justice of People with Psychosocial Disabilities] (2013), [http://sia.eurosocial-ii.eu/files/docs/1396253595-Protocolo\\_Costa\\_Rica\\_Acceso\\_](http://sia.eurosocial-ii.eu/files/docs/1396253595-Protocolo_Costa_Rica_Acceso_)

women with disabilities who are victims of violence should receive, in clear and accessible language, the following information: i) the place and manner to file a complaint; ii) the type of process and its different phases; iii) the purpose of their participation in the process; iv) their rights in the process, including the availability of supports and the possibility to obtain redress; v) court decisions.<sup>361</sup> This Protocol also requires training of police officers, prosecutors, social workers, and other professionals involved in prevention and protection services to women with disabilities.<sup>362</sup> It also requires the elimination of degrading reporting procedures and referral of victims of violence to social services rather than legal services so that “effective remedies” are provided for women with disabilities who experience violence.<sup>363</sup> In this regard, the CRPD Committee emphasizes the need for safe houses, support services, and procedures that are fully accessible and that provide effective protection from violence for women and children.<sup>364</sup> Finally, education and public awareness are essential in order to eliminate harmful stereotypes about women with disabilities.<sup>365</sup> Here, the media can play an important role in helping to eradicate stereotypes and raise awareness about the need to end violence against women and girls with disabilities.<sup>366</sup>

***E. Include Women with Disabilities as Decision Makers and Participants in All Programs and Policies that Affect Them***

Another important way to eliminate violence against women with disabilities is to ensure the effective participation by women with disabilities in the formulation of all relevant laws, policies, and

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Justicia\_personas\_discapacidad.pdf.

361 *Id.* at 35, 40.

362 *Id.* at 59. See also *General Comment No. 3: Article 6: Women and Girls with Disabilities*, *supra* note 9, ¶ 26.

363 PODER JUDICIAL DE COSTA RICA [Judiciary of Costa Rica], *supra* note 349, at 59.

364 *General Comment No. 2: Article 9*, *supra* note 201, ¶ 37.

365 *Cf.*, *An Assessment of the Social, Cultural and Institutional Factors that Contribute to the Sexual Abuse of Persons with Disabilities in East Africa*, ADVANTAGE AFRICA ET AL. (2016), <https://www.advantageafrica.org/file/advantage-africa-full-research-report-sexual-abuse-of-persons-with-disabilities-pdf>; see also *We can tell, we will tell Video*, DAWN/RAFH CAN., <http://www.dawncanada.net/issues/issues/we-can-tell-and-we-will-tell-2/we-can-tell-a-public-service-announcement/> (last visited Dec. 18, 2017).

366 *Media and Disability*, DISABILITY RIGHTS EDUCATION & DEFENSE FUND, [http://www.dredf.org/Media\\_and\\_Disability/index.shtml](http://www.dredf.org/Media_and_Disability/index.shtml) (last visited Dec. 18, 2017).

programs.<sup>367</sup> One of the most noteworthy accomplishments of the CRPD was the role of people with disabilities, themselves, in the drafting of the treaty. The phrase “Nothing About Us Without Us” became the rallying cry for the CRPD’s adoption, and since then, it continues to be used in many countries throughout the world.<sup>368</sup> Including women with disabilities in the development of laws, policies, and programs that affect them is essential to ensure their effectiveness and to foster collaboration among women’s rights groups, disabled peoples organizations, and other stakeholders involved in working to end violence against women and girls with disabilities.<sup>369</sup>

The CRPD Committee has itself recognized the importance of including women with disabilities in programs that affect them, including programs to combat violence. As it emphasized in its *General Comment Number 3*:

States Parties should reach out directly to women and girls with disabilities and establish adequate measures to guarantee that their perspectives are fully taken into account and that they will not be subjected to any reprisals for expressing their points of view and concerns, especially in relation to sexual and reproductive health and rights, as well as gender-based violence, including sexual violence.<sup>370</sup>

Moreover, views of women as helpless or “hopeless victims unwilling to change their circumstances” must change.<sup>371</sup> As the CRPD Committee itself has recognized, it is necessary to adopt affirmative action measures for the empowerment of women with disabilities, in consultation with their organizations.<sup>372</sup> In this

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367 See, e.g., *Concluding Observations Gabon*, *supra* note 39, ¶ 39; *Concluding Observations Mauritius*, *supra* note 21, ¶ 12; *Concluding Observations New Zealand*, *supra* note 21, ¶ 16; *Concluding Observations Peru*, *supra* note 182, ¶¶ 9, 15.

368 KANTER, *supra* note 8, at 9.

369 See *In Historic Move, UN Creates Single Entity to Promote Women’s Empowerment*, UN News (July 2, 2010), <http://www.un.org/apps/news/story.asp?NewsID=35224#.WkcjbbSGYU>.

370 *General Comment No. 3: Article 6, Women and Girls with Disabilities*, *supra* note 7, ¶ 23.

371 Michelle Fine & Adrienne Asch, *Disabled Women: Sexism without the Pedestal*, 8 J. SOC. & SOC. WELFARE 233, 241 (1981).

372 *General Comment No. 3: Article 6: Women and Girls with Disabilities*, *supra* note 7, ¶

context, the *Collectivo Chuhcan* in Mexico provides a model of a group of women with psychosocial disabilities who had experienced violence, many as residents of institutions.<sup>373</sup> In response, they developed a self-help and peer-to-peer support program.<sup>374</sup> The goal of their program is to empower women with disabilities and to train them as self-advocates.<sup>375</sup>

In the United States, the World Institute on Disability (WID) has developed the Curriculum on Abuse Prevention and Empowerment (CAPE) Curriculum for people with disabilities. This program focuses on empowerment as a means to end violence against women and men with disabilities.<sup>376</sup> In addition, Women With Disabilities, an Australian NGO, and DAWN-RAFH, a Canadian NGO, provide resources on their websites for women with disabilities about ending violence against women and girls with disabilities, using a human rights approach.<sup>377</sup> The active leadership of women with disabilities in these organizations has been their key to success.

#### **F. Provide Training for Justice Sector Professionals**

Although women with disabilities must remain at the center of programs that affect them, they need allies, including professionals involved in the justice system. Training of professionals involved at every level of the justice system is, therefore, an essential component in successful programs that seek to end violence against women with disabilities. For example, in its concluding observations in response to Luxembourg's recent country report, the CRPD Committee recommended specifically that the State Party "[e]nsure[s] that members of the police, judiciary, health and social services receive regular and mandatory training on the prevention of violence and

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64(b).

373 HANDICAP INT'L, *supra* note 89, ¶ 7, 7A.

374 HANDICAP INT'L, *supra* note 46, at 42–44.

375 *Id.*

376 WORLD INST. ON DISABILITY, CURRICULUM ON ABUSE, PREVENTION AND EMPOWERMENT, CAPE OF SELF-PROTECTION FOR PEOPLE WITH DISABILITIES AND ELDERS LIVING INDEPENDENTLY (2009).

377 See WOMEN WITH DISABILITIES AUSTL., <http://wwda.org.au> (last visited Apr. 23, 2018); see also Carolyn Frohmader, *Assessing the Situation of Women with Disabilities in Australia – A Human Rights Approach*, WOMEN WITH DISABILITIES AUSTRALIA (2011); see generally DAWN-RAFH CAN., <https://www.dawnCanada.net/about/our-mission-and-vision/> (last visited Apr. 23, 2018).



abuse of persons with disabilities.”<sup>378</sup>

In addition to training of professionals, the justice system itself, including all of its buildings and services, must be accessible to women and girls with disabilities who may have a range of accommodation needs. For example, as noted above, and as the CRPD Committee has acknowledged in its concluding observations, many courthouses and other facilities are not accessible to people with disabilities.<sup>379</sup> Moreover, police and prosecutors are often reluctant to open investigations and prosecute cases of violence against women with disabilities.<sup>380</sup> Such reluctance is often based on inappropriate stereotypes that women with disabilities are not credible or capable of giving or refusing consent to sex.<sup>381</sup> Such practices and attitudes must change and training provides an opportunity for such change.

The CRPD Committee has expressed its concern about the lack of training on or protocols for interviewing women with disabilities who are victims or witnesses in cases of violence,<sup>382</sup> as well as the lack of appropriate accommodations in judicial proceedings,<sup>383</sup> and the lack of “gender-sensitive and age-appropriate accommodations.”<sup>384</sup> According to the CRPD Committee, many of these barriers exist because of structural discrimination that leads to discriminatory institutional behavior, traditions, social norms and/or rules that promote rather than refute gender and disability stereotyping.<sup>385</sup>

Moreover, a study in Europe about access to justice for people with psychosocial disabilities found that their rights are not protected because of the lack of support and special measures within the justice system that could facilitate their access to procedures

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378 *Concluding Observations Luxembourg*, *supra* note 324, ¶ 33(e).

379 *See, e.g., Concluding Observations Brazil*, *supra* note 69, at ¶ 26.

380 *See, e.g., Concluding Observations Gabon*, *supra* note 39, ¶ 38; *Concluding Observations Mauritius*, *supra* note 21, ¶ 27.

381 *See, e.g., Concluding Observations El Salvador*, *supra* note 20, ¶ 29; *Concluding Observations Gabon*, *supra* note 39, ¶ 38; *Concluding Observations Kenya*, *supra* note 39, ¶ 25.

382 *See, e.g., Concluding Observations El Salvador*, *supra* note 20, ¶ 30; *Concluding Observations Mongolia*, *supra* note 182, ¶ 22.

383 *See, e.g., Concluding Observations El Salvador*, *supra* note 20, ¶ 30; *Concluding Observations Kenya*, *supra* note 39, ¶ 25; *Concluding Observations Mongolia*, *supra* note 182, ¶ 22.

384 *See, e.g., Concluding Observations Brazil*, *supra* note 69, ¶¶ 26–27.

385 *General Comment No. 3: Article 6: Women and Girls with Disabilities*, *supra* note 7, ¶ 17.



and information.<sup>386</sup> In this context, it is essential to provide support to women and girls with disabilities when they require it. Such support could include the option of having someone they trust or a trained professional accompany them throughout the judicial process. Such suggestions are included as examples of good practices in the “Protocol of attention for the effective access to justice of people with psychosocial disabilities” of Costa Rica.<sup>387</sup> Further, to reduce anxiety among women with disabilities who testify against their perpetrators, the Protocol recommends, as an accommodation, the right of the victims to testify outside of the presence of the defendant.<sup>388</sup>

In addition, during the testimony, statement, or questioning process, it is essential to have clear and simple questions, to consider the circumstances of each case, and to take into account the intersectional discrimination based on disability condition, age, level of education, and sociocultural factors, among others.<sup>389</sup> Moreover, Israel recently enacted what may be the first such law, requiring accommodations for people with disabilities in the criminal and civil justice systems.<sup>390</sup> This law, the Investigation and Testimony Procedural Act, was enacted in 2005<sup>391</sup> in response to a 1995 report by Bizchut, the Israel Center for Human Rights of People with Disabilities.<sup>392</sup> This report found widespread problems in accessing

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386 INCLUSION EUR., JUSTICE, RIGHTS AND INCLUSION FOR PEOPLE WITH INTELLECTUAL DISABILITY 28–30 (Cornell Univ. ed. 2007), <http://digitalcommons.ilr.cornell.edu/cgi/viewcontent.cgi?article=1279&context=gladnetcollect> (Austria, Cyprus, Czech Republic, France, Latvia, Liechtenstein, Norway, Poland, Romania, and Sweden require people with disabilities having a full legal capacity and proving their direct interest in the matter). *See also* EUR. UNION AGENCY FOR FUNDAMENTAL RIGHTS, ACCESS TO JUSTICE IN EUROPE: AN OVERVIEW OF CHALLENGES AND OPPORTUNITIES (2011).

387 Protocol of Attention for Effective Access to Justice of People with Psychosocial Disabilities, *supra* note 360, at 33, 36. According to the Protocol, such supports should include: i) the respect of the rights, will and preferences of the person and ensuring adequate communication; ii) alternatives to the substitute decision-making model in the decision-making process; and iii) avoiding conflict of interest and undue influence, or abuses. *Id.*

388 *Id.* at 36.

389 *Id.* at 29, 36.

390 Int’l Disability All., *Suggestions for Disability-Relevant Recommendations to be Included in the Concluding Observations of the Committee for the Elimination of Discrimination Against Women*, 48th session, ¶ 70 (Feb. 4, 2011).

391 *Id.*

392 KANTER, *supra* note 8, at 229.

justice for men and women with disabilities. The new law ensures protections and access to justice for people with disabilities who are witnesses and victims as well as suspects and perpetrators.<sup>393</sup> One of the most unique aspects of the law is the creation of a new public position, known as the Special Investigator, who is trained and responsible for communicating with people who have intellectual or psychosocial disabilities.<sup>394</sup> In addition to the law, Bizchut has prepared a guide to train police and other court personnel on how to communicate with people who have communication, psychosocial, or intellectual disabilities by using, when appropriate, alternative and augmentative communication devices, as well as pictures and communication boards.<sup>395</sup> This Guide also highlights the importance of listening carefully and respectfully to victims, and giving credibility to their testimony and statements.<sup>396</sup>

### VIII. Conclusion

Women with disabilities face discrimination throughout the world based on their gender and disability. Such multiple and intersectional discrimination has resulted in higher rates of gender-based violence among women and girls with disabilities than for women and girls without disabilities. Violence against women and girls with disabilities occurs at home and in institutions, perpetrated by intimate partners, family members and neighbors, as well as by care takers and personal assistants. When such violence occurs, women and girls with disabilities face significant and unique barriers in attempting to report it, especially if it is sexual violence. Further, as a result of laws and policies that deprive women with disabilities of legal capacity and perpetuate myths about their disability, generally, and their sexuality, in particular, women with disabilities often have no recourse in the judicial system. As Stephanie Ortoleva has written, “sometimes the justice system remedies inequality and discrimination, and sometimes it is the justice system itself that perpetuates that very inequality and discrimination.”<sup>397</sup>

393 Int'l Disability All., *supra* note 390.

394 *Id.*

395 SHARON PRIMOR & NA'AMA LERNER, *The Right Of Persons With Intellectual, Psychosocial and Communications Disabilities to Access Justice and Accommodations In The Criminal Process* 11 (Bizchut ed., 2010), <http://bizchut.org.il/he/wp-content/uploads/2015/01/Booklet-The-right-of-persons-with-disabilities-to-access-to-justice.pdf>.

396 *Id.* at 9–10.

397 Ortoleva, *supra* note 89, at 285.

In 2012, Professor Hope Lewis and Stephanie Ortoleva called attention to the issue of violence against women with disabilities in their groundbreaking publication, *Forgotten Sisters: A Report on Violence Against Women with Disabilities: A Review of its Nature, Scope, Causes and Consequences*. Since then, there has been increased awareness about violence against girls and women with disabilities as well the adoption of new legal protections. These new international, regional, and domestic laws, as well as the work of the CRPD Committee in reviewing country reports and issuing General Comments, aim not only to provide assistance to the victims of violence, but also to ensure the accountability of States Parties in protecting them from violence in the first place, and in prosecuting their perpetrators, after the fact. It is our hope that with greater awareness about and full implementation of these international, regional, and domestic laws, policies, and violence prevention programs, violence, abuse, and exploitation of women and girls with disabilities will, once and for all, come to an end.

## Hope, Dignity, and the Limits of Democracy\*

*Berta Esperanza Hernández-Truyol\*\**

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\* This essay is based upon remarks delivered on November 17, 2017, for a symposium in honor of Hope Lewis. The purpose of the symposium, titled *International Law, Local Justice: Human Rights Transformed*, was to celebrate Hope Lewis's work. In this regard, the author wants to thank Hope Lewis for her dedication to justice and her inspirational work.

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As an African American feminist law professor who is visually impaired and the daughter of immigrants, I am often torn as to which social justice organizing conference to attend first on any given day.

Hope Lewis<sup>1</sup>

Wise [one] lookin' in a blade of grass  
 Young [one] lookin' in the shadows that pass  
 Poor [one] lookin' through painted glass  
 For dignity

Bob Dylan<sup>2</sup>

## I. Introduction

Dignity, fairness, and human rights are values that serve to promote justice; values that Professor Hope Lewis fully and passionately embraced. These ideals, respected and promoted in international and domestic spheres alike, are interdependent and require coordinated deployment in order to render justice for the marginable a reality.<sup>3</sup> Hope realized that the attainment of justice, a goal that guided her life and work, requires a multidimensional approach that recognizes the indivisibility and interdependence of human rights, as only such a complex approach effectuates a meaningful anti-subordination strategy.<sup>4</sup> Multidimensionality

1 Hope Lewis, *Global Intersections: Critical Race Feminist Human Rights and International Black Women*, 50 ME. L. REV. 309, 309 (1998) [hereinafter Lewis, *Global Intersections*]. For a concise definition of intersectionality, see CHRISTIE LAUNIUS & HOLLY HASSEL, THRESHOLD CONCEPTS IN WOMEN'S AND GENDER STUDIES: WAYS OF SEEING, THINKING AND KNOWING 194 (2015) (noting that intersectionality refers to “[t]he ways multiple forms of oppression and identity interact to create someone’s experience of and access to social influence and individual and institutional power”).

2 BOB DYLAN, *Dignity*, on BOB DYLAN'S GREATEST HITS VOLUME 3 (Sony Music Entertainment Inc. 1994) (license taken with lyrics by author to render them gender-neutral).

3 See Berta Esperanza Hernández-Truyol, *Glocalizing Women's Health and Safety: Migration, Work and Labor*, 15 SANTA CLARA J. INTL. L. 48, 51 (2017) [hereinafter Hernández-Truyol, *Glocalizing*] (defining *marginableness* as a word that “fills a linguistic void existing in the current conversations about migrants, among others, who are both vulnerable and marginalized”).

4 In this context, *multidimensionality* is the concept that every person is comprised of myriad layers of identity, including race, sex, ethnicity, sexuality, language, and religion. See generally Berta Esperanza Hernández-Truyol, *LatIndia II — Latinas/os, Natives, and Mestizajes — A LatCrit Navigation of Nuevos Mundos*,

requires the reconceptualization of the linear approach to law that easily allows the marginalization and invisibility of those who most need to emerge from the shadows of the law. Hope's mission was to clear the path of legal obstacles and obfuscations for the marginable.

Hope Lewis dedicated her life to this justice project. This essay, written to celebrate her life and legacy, will first focus on Professor Lewis's dream. Next, the piece focuses on dignity as a site in which to instantiate and promote Professor Lewis's vision. In this segment, I will travel the path of the symposium *International Law, Local Justice: Human Rights Transformed* to address both the international and United States' positions on dignity and discuss a contentious contemporary concern—LGBT rights—that clearly exposes the importance of accepting an indivisibility framework.<sup>5</sup> In so doing, the essay unveils the tension between dignitarian rights—those rights that human beings are entitled to simply because of their humanity—and democracy, another interest of high value both domestically and internationally. The piece closes by suggesting a paradigm that reflects Hope's vision of justice—the indivisibility and interdependence conceptualization of rights—and that enables protection of and respect for dignitarian rights.

## II. Hope Lewis and the Search for Justice

It is appropriate to begin this essay by reflecting upon Hope, the person who inspired the conference and in whose honor I write these words. Hope was social justice. (My translation.) The indivisibility paradigm of the human rights discipline to which she gravitated and that she enriched with her scholarship made sense because of those indivisible intersections that Hope embodied: immigrant family, visually-impaired, feminist, African-American, woman, internationalist. Her focus on economic, social, and cultural (ESC) rights was not accidental. All her work

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*Nuevas Fronteras, and Nuevas Teorias*, 33 U.C. DAVIS L. REV. 851 (2000); Berta Esperanza Hernández-Truyol, *Latina Multidimensionality and LatCrit Possibilities: Culture, Gender, and Sex*, 53 U. MIAMI L. REV. 811 (1999); Berta Esperanza Hernández-Truyol, *Borders (En)Gendered: Normativities, Latinas, and a LatCrit Paradigm*, 72 N.Y.U. L. REV. 882 (1997).

5 An "indivisibility framework" of human rights recognizes that human rights do not exist in isolation and that people cannot truly enjoy any of their rights if others are withheld. The right to vote means little to a person living in privation.



pursued fairness and integrity. To attain this end, her scholarship emphasized, as a foundation, the centrality of ESC rights, often ignored and viewed as second-class rights in human rights discourse, to an examination of human thriving.<sup>6</sup>

Hope engaged this model with the full realization that oftentimes even judicial approaches that established the justiciability of ESC rights did not always translate to justice on the ground. For example, even in South Africa, with its beautiful and inclusive constitution, the recognized right to health does not mean everyone in need can get treatment.<sup>7</sup> Similarly, the

6 See generally Hope Lewis, *Human Rights and the Global Economy: The Promises and Failures of Globalization*, in PROGRESSIVE LAWYERING, GLOBALIZATION AND MARKETS: RETHINKING IDEOLOGY AND STRATEGY (Clare Dalton ed., 2007) [hereinafter Lewis, *Human Rights and the Global Economy*]; Hope Lewis, *New Human Rights: U.S. Ambivalence Toward the International Economic and Social Rights Framework*, in 1 BRINGING HUMAN RIGHTS HOME, A HISTORY OF HUMAN RIGHTS IN THE UNITED STATES 103 (Cynthia Soohoo et al. eds. 2008) [hereinafter Lewis, *New Human Rights*]; Hope Lewis, *Female Genital Mutilation and Female Genital Cutting*, in 2 ENCYCLOPEDIA OF HUMAN RIGHTS, DEMOCRACY PRODUCTION (David P. Forsythe ed., 2009) [hereinafter Lewis, *Female Genital Mutilation*]; Hope Lewis, *Race, Class, and Katrina: Human Rights and (Un)Natural Disaster*, in ENVIRONMENTAL JUSTICE IN THE NEW MILLENNIUM – GLOBAL PERSPECTIVES ON RACE, ETHNICITY, AND HUMAN RIGHTS, (Filomina Chioma Steady ed., 2009) [hereinafter Lewis, *Race, Class, and Katrina*]; Hope Lewis, *Between Irua and “Female Genital Mutilation”: Feminist Human Rights Discourse and the Cultural Divide*, 8 HARV. HUM. RTS. J. 1 (1995) [hereinafter Lewis, *Between Irua*]; Hope Lewis, *Embracing Complexity: Human Rights in Critical Race Feminist Perspective*, 12 COLUM. J. GENDER & L. 510 (2003) [hereinafter Lewis, *Embracing Complexity*]; Lewis, *Global Intersections*, *supra* note 1; Hope Lewis, *Transnational Dimensions of Race in America*, 72 ALBANY L. REV. 999 (2009) [hereinafter Lewis, *Transnational Dimensions*]; STEPHANIE ORTOLEVA & HOPE LEWIS, NORTHEASTERN PUBLIC LAW & THEORY FACULTY RESEARCH PAPER SERIES No. 104-2012, FORGOTTEN SISTERS – A REPORT ON VIOLENCE AGAINST WOMEN WITH DISABILITIES: AN OVERVIEW OF ITS NATURE, SCOPE, CAUSES AND CONSEQUENCES (2012), <https://repository.library.northeastern.edu/files/neu:332599/fulltext.pdf> [hereinafter ORTOLEVA & LEWIS, FORGOTTEN SISTERS].

7 See *Soobramoney v. Minister of Health, KwaZulu-Natal* 1998 (1) SA 765 (CC) (S. Afr.). In *Soobramoney*, a state hospital had a policy providing that only patients who had treatable and remediable acute renal failure had automatic access to dialysis at the hospital. *Id.* at 769 para. 3. Those with irreversible chronic failure did not have automatic access. *Id.* *Soobramoney*, a 41-year-old man suffering from chronic renal failure, did not meet the hospital’s guidelines for accepting patients with chronic renal failure for dialysis treatment. *Id.* at 769 para. 1. *Soobramoney* could not afford private treatment. *Id.* at 770 para. 5. Consequently, he sought an order from the courts mandating the hospital to provide him treatment. *Id.* His request ultimately reached the Constitutional

right to housing does not signify that those who need shelter will have access to it.<sup>8</sup> Indeed, the South African cases *Soobramoney* and *Grootboom* underscore the reality that the existence of a right without access to its realization exacerbates the tragedy of human rights privations.<sup>9</sup>

Because Professor Lewis was determined to unearth every threat to individual and group rights, she looked at human rights failings globally and with respect to all categories of rights.<sup>10</sup> In so doing, she often exposed the U.S.'s troubling history in fulfilling not only civil and political rights, but also economic, social, and cultural rights domestically.<sup>11</sup> She unveiled the hypocrisy of the U.S. claiming global leadership in the promotion of, and insistence upon respect for, civil and political rights when its own house was not in order.<sup>12</sup> Moreover, she denounced the U.S.'s failure to embrace the existence of ESC rights.<sup>13</sup> Her passion drove her to underscore the indivisibility of the myriad human rights necessary for human thriving.

Hope was passionate about those to whom I refer as marginable<sup>14</sup>—those who are invisible: the oppressed, the

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Court of South Africa, which concluded that the state engaged in acceptable management of its resources and that the guidelines did not result in a violation of *Soobramoney's* constitutional rights to emergency treatment or to life. *Id.* at 770 para. 6, 773–74 paras. 19–21, 778 para. 36.

8 See *Government of the Republic of South Africa v. Grootboom* 2001 (1) SA 46 (CC) (S. Afr.). A municipality ordered to provide a bare minimum of shelter, sanitation, and water to persons who were awaiting availability of subsidized housing challenged the decision. *Id.* at 53–54 para. 4. The Constitutional Court concluded that the state must give effect to the constitution's grant of a right to adequate housing. *Id.* at 86 para. 96. Notwithstanding the Court's decision, Ms. Grootboom, whose name the case bears, died homeless eight years after the decision. Pearlie Joubert, *Grootboom Dies Homeless and Penniless*, MAIL & GUARDIAN (Aug. 8, 2008, 10:45 AM), <https://mg.co.za/article/2008-08-08-grootboom-dies-homeless-and-penniless>.

9 See *Soobramoney*, 1998 (1) SA 765 (CC) (S. Afr.); *Grootboom*, 2001 (1) SA 46 (CC) (S. Afr.).

10 See generally Lewis, *Human Rights and the Global Economy*, *supra* note 6; Lewis, *New Human Rights*, *supra* note 6; Lewis, *Female Genital Mutilation*, *supra* note 6; Lewis, *Race, Class, and Katrina*, *supra* note 6; Lewis, *Between Irua*, *supra* note 6; Lewis, *Embracing Complexity*, *supra* note 6; Lewis, *Global Intersections*, *supra* note 1; Lewis, *Transnational Dimensions*, *supra* note 6; ORTOLEVA & LEWIS, *FORGOTTEN SISTERS*, *supra* note 6.

11 Lewis, *New Human Rights*, *supra* note 6, at 115.

12 *Id.*

13 See *id.* at 103–04.

14 Hernández-Truyol, *Glocalizing*, *supra* note 3.

marginalized, the vulnerable. She wrote about race,<sup>15</sup> disability,<sup>16</sup> critical race feminism,<sup>17</sup> intersectionality,<sup>18</sup> class,<sup>19</sup> economic rights,<sup>20</sup> and gender.<sup>21</sup> All her work was quintessentially about anti-subordination.

### III. Dignity

#### A. *The Idea of Dignity*

The passion driving Professor Lewis's work was her dedication to human flourishing. As such, her observations and ruminations were, in essence, about attaining human dignity, a condition of which the marginable are deprived. As the Bob Dylan lyrics quoted in the epigraph suggest, although everyone seeks and desires dignity, it is a condition that may be difficult to realize. Significantly, dignity is a word that defies simple definition.

Dignity, moreover, does not have a uniform meaning; its meaning depends on context. Different persons can interpret or understand the concept differently based on geography, environment, perspective, and circumstances. The concept also differs among cultures—and culture and cultural expressions are values protected by the human rights system.<sup>22</sup>

Dictionaries define *dignity* as “[t]he state or quality of being worthy of honour or respect”,<sup>23</sup> “being worthy, honored, or esteemed.”<sup>24</sup> In my view, dignity translates to experiencing the conditions necessary for human flourishing,<sup>25</sup> for the fulfillment of

15 Lewis, *Transnational Dimensions*, *supra* note 6.

16 ORTOLEVA & LEWIS, *FORGOTTEN SISTERS*, *supra* note 6.

17 Lewis, *Embracing Complexity*, *supra* note 6.

18 Lewis, *Global Intersections*, *supra* note 1.

19 Lewis, *Race, Class, and Katrina*, *supra* note 8.

20 Lewis, *Human Rights and the Global Economy*, *supra* note 6.

21 Lewis, *Female Genital Mutilation*, *supra* note 6; Lewis, *Between Irua*, *supra* note 6.

22 See, e.g., International Covenant on Civil and Political Rights, art. 27, *opened for signature* Dec. 16, 1966, 999 U.N.T.S. 171 [hereinafter ICCPR].

23 *Dignity*, OXFORD DICTIONARIES, <https://en.oxforddictionaries.com/definition/dignity> (last visited Jan. 12, 2018).

24 *Dignity*, MERRIAM-WEBSTER DICTIONARIES, <https://www.merriam-webster.com/dictionary/dignity> (last visited Jan. 12, 2018).

25 See Hernández-Truyol, *Glocalizing*, *supra* note 3, at 54–55; See generally BERTA ESPERANZA HERNÁNDEZ-TRUYOL & STEPHEN J. POWELL, *JUST TRADE: A NEW COVENANT LINKING TRADE AND HUMAN RIGHTS* (2009); *MORAL IMPERIALISM: A CRITICAL ANTHOLOGY* (Berta Esperanza Hernández-Truyol ed., 2002); Berta Esperanza Hernández-Truyol & Sharon E. Rush,

the human spirit,<sup>26</sup> and for reaching our human capabilities.<sup>27</sup>

Persons can experience dignity, or its affront, in many aspects of life. For example, a dignity umbrella has been developed that suggests the necessary values to protect and maintain a patient's dignity.<sup>28</sup> Care, courtesy, privacy, safety, respect, kindness, choice, humanity, equality, voice, independence, and diversity are words that people use to describe what dignity means to them.<sup>29</sup> These components, listing the specifications prerequisite to the fulfillment of dignity, are informative of the human condition<sup>30</sup> and reflect civil, social, economic, and cultural rights. Equally instructive, however, are the words people use to describe how they feel upon an affront to their dignity. The words, which include trauma, fear, powerlessness, humiliation, embarrassment, worthlessness, vulnerability, anger, and sadness,<sup>31</sup> reflect economic, social, cultural, political, and psychological insecurities. Thus, although it is difficult to ascertain precisely what dignity means, it is not difficult to identify the consequences of its deprivation. A life with dignity is a life that experiences the fulfillment of human rights; a life without dignity reflects a denial of such rights.

Throughout history, and sad to say not too long ago, not all were deemed to deserve conditions of dignity. In India the caste system remains, if not in law,<sup>32</sup> in fact.<sup>33</sup> The legally prohibited

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*Culture, Nationhood, and the Human Rights Ideal*, 33 U. MICH. J.L. REFORM 233, 5 MICH. J. RACE & L. 817 (2000).

26 See Hernández-Truyol, *Glocalizing*, *supra* note 3, at 54; Hernández-Truyol & Rush, *supra* note 25, at 234, 243; Berta Hernández-Truyol et al., *Beyond the First Decade: A Forward-Looking History of LatCrit Theory, Community and Praxis*, 17 BERKELEY LA RAZA L.J. 169, 204 (2015).

27 See generally AMARTYA SEN, *DEVELOPMENT AS FREEDOM* (1999).

28 See *The Dignity Umbrella on Digital Rights and Responsibilities*, THINGLINK, <https://www.thinglink.com/scene/849984955223113730> (last visited Apr. 30, 2018).

29 See *id.*

30 See, e.g., Jeff Malpas, *Human Dignity and Human Being*, in *PERSPECTIVES ON HUMAN DIGNITY: A CONVERSATION* 19–25 (Jeff Malpas & N. Lickiss eds., 2007), <http://www.jus.uio.no/smr/english/about/current/events/2015/malpas-human-dignity-and-human-being.pdf>.

31 See, e.g., *Dignity*, EMOTIONAL COMPETENCY, <http://www.emotionalcompetency.com/dignity.htm> (last visited Dec. 6, 2017).

32 See INDIA CONST. art. 14 (mandating equality in law); *id.* art. 15, §1 (prohibiting discrimination on the basis of, among other things, caste); *id.* art. 17 (abolishing and prohibiting untouchability).

33 See, e.g., *What Is India's Caste System?*, BBC NEWS (July 20, 2017), <http://www.bbc.com/news/world-asia-india-35650616>; Mari Marcel Thekaekara, *India's*

category of “untouchable” still exists, and the persons assigned to this category live in conditions of deep privation.<sup>34</sup>

In the U.S. there is the narrative of conquest of American Indians and the taking of their land as well as the horrific history and legacy of slavery, an institution that facilitated economic growth for the slave owner and commodified and dehumanized the slave. Currently, the economic status of the U.S. population reflects this shameful story of slavery and colonization.<sup>35</sup> In 2016, 40.6 million people in the U.S. were living in poverty and 13% of households were food insecure.<sup>36</sup> These huge numbers, unacceptable in undifferentiated categories, become more perverse upon consideration of the persistent racial disparities in the data: 26.2% of Native Americans, 22% of African Americans, 19.4% of Latinas/os, yet only 8.8% of whites fell below the poverty line in 2016.<sup>37</sup> In other words, people are existing without enjoyment of their human rights. In order to search for possible solutions, it is appropriate to investigate legal sources for potential grounds to challenge the existing global disparities—disparities that can be analyzed on dignitarian grounds.

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*Caste System Is Alive and Kicking – and Maiming and Killing*, THE GUARDIAN (Aug. 15, 2016), <https://www.theguardian.com/commentisfree/2016/aug/15/india-caste-system-70-anniversary-independence-day-untouchables>; Ravi Agrawal, *India's Caste System: Outlawed, but Still Omnipresent*, CNN (Feb. 23, 2016), <http://www.cnn.com/2016/02/23/asia/india-caste-system/index.html>.

34 See *What Is India's Caste System?*, *supra* note 33; Thekaekara, *supra* note 33; Agrawal, *supra* note 33.

35 Heather A. O'Connell, *The Impact of Slavery on Racial Inequality in Poverty in the Contemporary U.S. South*, 90 SOC. FORCES 713 (2012), <https://academic.oup.com/sf/article/90/3/713/2235802>.

36 *Poverty and Hunger Fact Sheet*, FEEDING AMERICA (Sept. 2017), <http://www.feedingamerica.org/assets/pdfs/fact-sheets/poverty-and-hunger-fact-sheet.pdf>; see also JESSICA L. SEMEGA ET AL., U.S. CENSUS BUREAU, *INCOME AND POVERTY IN THE UNITED STATES: 2016*, P60-259 13 (2017), <https://www.census.gov/content/dam/Census/library/publications/2017/demo/P60-259.pdf>.

37 SEMEGA ET AL., *supra* note 36; Valerie Wilson & Zane Mokhiber, *2016 ACS Shows Stubbornly High Native American Poverty and Different Degrees of Economic Well-being for Asian Ethnic Groups*, ECON. POLICY INST.: WORKING ECONOMICS BLOG (Sept. 15, 2017, 3:06 PM), <https://www.epi.org/blog/2016-acp-shows-stubbornly-high-native-american-poverty-and-different-degrees-of-economic-well-being-for-asian-ethnic-groups/>.

### ***B. The Legal Foundations of Dignity — Human Rights Documents***

In seeking a legal foundation for dignity, human rights norms are informative and valuable, as they explicitly write dignity into the law. However, before this work embraces the concept of human rights, it is appropriate first to acknowledge that, as it exists, the human rights framework is a flawed human ideal. I have elsewhere noted that the human rights system is complicated.<sup>38</sup> It can be, and indeed has been, critiqued. The human rights system from which this essay draws rights, often honored in the breach with respect to migrants, women, ethnic and racial minorities, sexual minorities, religious minorities, and disadvantaged economic classes, to name a few, is not perfect, as Hope pointed out in her work. It has Western, heteronormative, patriarchal, colonialist, racialized, and sexist foundations that both compel rejection and invite reformation.<sup>39</sup> These imperfect structures have subjected the system to Asian,<sup>40</sup> Southern,<sup>41</sup> feminist,<sup>42</sup> and Third World/anti-colonialist<sup>43</sup> critiques. This work embraces a reimagined human rights system that is egalitarian, equitable, intersectional/multidimensional,<sup>44</sup> and multidisciplinary—it considers not only law but also sociology, psychology, economics, and science—in the ultimate pursuit of human flourishing. Such a system serves all human beings well, particularly the marginable.

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38 See, e.g., Berta Esperanza Hernández-Truyol, *Human Rights, Globalization, and Culture: Centering Personhood in International Narrative*, in *MORAL IMPERIALISM*, *supra* note 25, at 355–58.

39 I have suggested reforming these foundations to remedy the biases they cause, and it is with that reformed model in mind that I offer this principle—a reimagined and equitable human rights system—as an organizing principle for the feminist project. See generally *id.*

40 See generally WM. THEODORE DE BARY, *ASIAN VALUES AND HUMAN RIGHTS: A CONFUCIAN COMMUNITARIAN PERSPECTIVE* (1998).

41 “Southern” here refers to the Global South. See generally BALAKRISHNAN RAJAGOPAL, *INTERNATIONAL LAW FROM BELOW: DEVELOPMENT, SOCIAL MOVEMENTS AND THIRD WORLD RESISTANCE* (2003).

42 See generally *INTERNATIONAL LAW: MODERN FEMINIST APPROACHES* (Doris Buss & Ambreena Manji eds., 2005); see also *GLOBAL CRITICAL RACE FEMINISM: AN INTERNATIONAL READER* (Adrien Katherine Wing ed., 2000).

43 See generally ANTHONY ANGHIE, *IMPERIALISM, SOVEREIGNTY AND THE MAKING OF INTERNATIONAL LAW* (2004).

44 See, e.g., Berta Esperanza Hernández-Truyol, *Building Bridges — Latinas and Latinos at the Crossroads: Realities, Rhetoric and Replacement*, 25 *COLUM. HUM. RTS. L. REV.* 369 (1994).



Such is the system that Hope worked incessantly to build.

To be sure, human rights documents, on paper, affirm that dignity is a prerequisite for human thriving and show that dignity is central to the fulfillment of the human condition. The United Nations (U.N.) Charter's Preamble specifically provides, "We the peoples of the United Nations . . . reaffirm faith in fundamental human rights, in the dignity and worth of the human person, in the equal rights of men and women . . ." <sup>45</sup> Similarly, the Universal Declaration of Human Rights (UDHR) uses the word *dignity*—it appears five times. <sup>46</sup> First, the UDHR's Preamble reaffirms the Charter's preambular language. <sup>47</sup> Next, Article 1 presents the foundation of human rights as dignitarian: "All human beings are born free and equal in dignity and rights." <sup>48</sup> The juxtaposition of dignity and rights informs us of the innate nature of dignity for all. Thus the UDHR, the blueprint for the human rights legal framework, fully centers dignity.

Similarly, the Universal Declaration on Bioethics and Human Rights (UDBHR) makes multiple references to *dignity*. <sup>49</sup> Article 3 provides that "human dignity, human rights and fundamental freedoms are to be fully respected." <sup>50</sup> In the same article, the UDBHR prioritizes the individual over science or society. <sup>51</sup>

The International Covenant on Civil and Political Rights (ICCPR) is significant not only because it, too, centers dignity, but also because its Preamble recognizes that all human rights are indivisible and emerge from the inherent dignity of the human person. <sup>52</sup> The ICCPR specifically protects the rights to equality

45 Charter of the United Nations, pmbl., June 26, 1945, 1 U.N.T.S. XVI.

46 G.A. Res. 217 (III) A, pmbl., arts. 1, 22, 23, Universal Declaration of Human Rights (Dec. 10, 1948)[hereinafter UDHR].

47 UDHR, *supra* note 46, pmbl. ("Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world . . .").

48 *Id.* at art. 1.

49 Education, Scientific and Cultural Organization Res. 33/36 (Oct. 21, 2005) (using *dignity* twelve times).

50 *Id.* at art. 3(1).

51 *Id.* at art. 3(2).

52 ICCPR, *supra* note 22, pmbl. ("Recognizing that these rights derive from the inherent dignity of the human person; Recognizing that, in accordance with the Universal Declaration of Human Rights, the ideal of free human beings enjoying civil and political freedom and freedom from fear and want can only be achieved if conditions are created whereby everyone may enjoy his civil and



and non-discrimination,<sup>53</sup> as well as the rights to association,<sup>54</sup> life,<sup>55</sup> privacy,<sup>56</sup> personal security,<sup>57</sup> culture,<sup>58</sup> and to participate in democratic governance.<sup>59</sup>

The International Covenant on Economic, Social and Cultural Rights (ICESCR), in its Preamble, also recognizes “the inherent dignity and . . . the equal and inalienable rights of all members of the human family . . . [as] the foundation of freedom, justice and peace in the world.”<sup>60</sup> The same sentence emphasizes the equal and inalienable rights of all members of the human family. These equal and inalienable rights are economic, social, and cultural rights recognized in the ICESCR. But the recognition of the indivisibility of rights signifies that civil and political rights are intimately related to economic rights.<sup>61</sup> These ESC rights specifically include the right to equality and non-discrimination,<sup>62</sup> the right to health,<sup>63</sup> the right to education,<sup>64</sup> the right to work,<sup>65</sup> the right to good conditions at work,<sup>66</sup> and the right to culture.<sup>67</sup> Beyond the preambular language in both the ICCPR and the ICESCR that addresses the interdependence of civil and political rights on the one hand and economic, social, and cultural rights on the other,<sup>68</sup> dignity provides the tie that elucidates the interdependence of these sets of rights. For example, dignitarian realities tell us that the right to participate in democratic

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political rights, as well as his economic, social and cultural rights. . . .”).

53 *Id.* art. 2, ¶ 1; *id.* art. 26.

54 *Id.* art. 22.

55 *Id.* art. 6.

56 *Id.* art. 17.

57 *Id.* art. 9.

58 *Id.* art. 27.

59 *Id.* art. 25.

60 International Covenant on Economic, Social and Cultural Rights, pmbl., *opened for signature* Dec. 16, 1966, 993 U.N.T.S. 3 [hereinafter ICESCR].

61 *Id.* (“Recognizing that, in accordance with the Universal Declaration of Human Rights, the ideal of free human beings enjoying freedom from fear and want can only be achieved if conditions are created whereby everyone may enjoy his economic, social and cultural rights, as well as his civil and political rights . . .”).

62 *Id.* art. 2.

63 *Id.* art. 12.

64 *Id.* art. 13.

65 *Id.* art. 6.

66 *Id.* art. 7.

67 *Id.* art. 15.

68 ICCPR, *supra* note 22, pmbl.; ICESCR, *supra* note 60, pmbl.

governance is meaningless to one living in privation—without food, shelter, or health.

One significant and recent treaty—indeed one on which Hope worked tirelessly—is the Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol.<sup>69</sup> This treaty, which was hugely significant for Professor Hope Lewis both personally and professionally, fully centers dignity. Its Preamble reiterates the U.N. Charter’s recognition of “the inherent dignity and worth . . . of all members of the human family”<sup>70</sup> and that “discrimination . . . on the basis of disability is a violation of the inherent dignity and worth of the human person.”<sup>71</sup> The CRPD’s Preamble concludes by noting that promotion and protection of the rights and dignity of persons with disabilities will promote the enjoyment of civil and political as well as social, economic, and cultural rights.<sup>72</sup> This language evinces the interdependence of rights that was so central to Hope’s work and is critical to the work of those of us who want to promote human flourishing.<sup>73</sup>

Article 1 of the CRPD articulates a primary purpose of the Convention as being to promote respect for the inherent dignity of persons with disabilities.<sup>74</sup> The first General Principle articulated in Article 3 includes “[r]espect for inherent dignity.”<sup>75</sup> Article 8 mandates States Parties to adopt measures to “foster respect for the rights and dignity of persons with disabilities.”<sup>76</sup> In Article 16, the CRPD requires States Parties to promote the recovery of persons covered by the Convention who have been victims of exploitation or abuse and provides that “[s]uch recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.”<sup>77</sup> In the context of education, Article 24 mandates that States Parties direct education of persons with disabilities to enable “[t]he full development of

69 Convention on the Rights of Persons with Disabilities, Dec. 13, 2006, 2515 U.N.T.S. 3 [hereinafter CRPD].

70 *Id.* pmb., ¶ a. See also Charter of the United Nations, *supra* note 45.

71 CRPD, *supra* note 69, pmb., ¶ h.

72 *Id.* pmb., ¶ y.

73 *Id.*

74 *Id.* art. 1.

75 *Id.* art. 3, ¶ a.

76 *Id.* art. 8, ¶ 1(a).

77 *Id.* art. 16, ¶ 4.

human potential and sense of dignity and self-worth . . . .”<sup>78</sup> Article 25, which addresses health, similarly centers dignity in requiring health professionals to provide care to persons covered by the Convention.<sup>79</sup> The centrality of dignity in the quest to provide equality to persons with disabilities and to enable the attainment of such persons’ human capabilities underscores its human essence.

It is useful to refer to other U.N. documents to appreciate the breadth and depth of the connection between dignity and the thriving of the human spirit. For example, the Vienna Declaration and Programme of Action<sup>80</sup> adopted by the 1993 World Conference on Human Rights reinforced the dignitarian foundations of human rights.<sup>81</sup> This conference is significant because it represents what the marginalized can accomplish with unity and strategy to pursue dignitarian aims. Although the Vienna Conference was a World Conference on Human Rights—a conference at which most would assume the participants would engage all marginable persons’ issues—women, who comprise at least half of the world’s population, and women’s issues were not anywhere to be found on the agenda. What happened at the Conference was both noteworthy and inspirational. Women from around the globe—South, North, East and West—of all races and religions, of diverse ethnicities and from all economic and educational backgrounds, came together and, centering the focus on the universal and ubiquitous problem of violence against women, demanded that the agenda incorporate women’s issues. Women, first rendered invisible by the absence of gender in the documents, reimagined and redirected the conference. The refocused agenda not only included gender issues, but it also centered them. The final document, the Vienna Declaration and Programme of Action, in the Preamble “recogniz[es] and affirm[s] that all human rights derive

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78 *Id.* art. 24, ¶ 1(a).

79 *Id.* art. 25.

80 World Conference on Human Rights, *Vienna Declaration and Programme of Action*, U.N. Doc. A/CONF.157/23 (June 25, 1993).

81 *See, e.g., id.* at 2 (“[A]ll human rights derive from the dignity and worth inherent in the human person, and . . . the human person is the central subject of human rights and fundamental freedoms . . . Recalling the Preamble to the Charter of the United Nations, in particular the determination to reaffirm faith in fundamental human rights, in the dignity and worth of the human person, and in the equal rights of men and women . . .”). The World Conference took place in June of 1993 in Vienna, Austria, and was attended by thousands of participants, including the author.

from the dignity and worth inherent in the human person” and continues to use *dignity* a total of ten times in the text.<sup>82</sup>

Also noteworthy in evaluating the significance of dignity to the human condition is the 1995 Fourth World Conference on Women in Beijing. There, the world first heard the now oft-quoted refrain: “[h]uman rights are women’s rights and women’s rights are human rights.”<sup>83</sup> Paragraph 8 of the Declaration from the Fourth World Conference reaffirmed the global community’s commitment to human dignity.<sup>84</sup> This provision, however, also explicitly raised the gender dimension by providing that the signatories were reaffirming their commitment to “[t]he equal rights and inherent human dignity of women and men . . . .”<sup>85</sup> This language recalls the feminist in Hope, wanting equality for all and dignity for all in spite of and because of the interdependent parts of their being.

Finally, the Yogyakarta Principles<sup>86</sup> and the Yogyakarta Principles plus 10,<sup>87</sup> which apply human rights law to sexual orientation, gender identity, gender expression and sex characteristics,<sup>88</sup> also embrace the centrality of dignity. For example, the Preamble of the Yogyakarta Principles provides that “all human beings are born free and equal in dignity.”<sup>89</sup> Following, Principle 1 expressly states, “All human beings are born free and equal in dignity and rights. Human beings of all

82 *Id.*

83 See Hillary Rodham Clinton, *Women’s Rights Are Human Rights*, 24 *WOMEN’S STUD. Q.* 98, 100 (1996); *Hillary Clinton: Women’s Rights are Human Rights*, *JSTOR DAILY* (July 25, 2016), <https://daily.jstor.org/hillary-clinton-womens-rights-are-human-rights/>.

84 Fourth World Conference on Women, *Beijing Declaration and Platform for Action*, U.N. Doc. A/CONF.177/20/Rev.1, annex I, ¶ 8 (Sep. 1995).

85 *Id.* ¶ 8.

86 INT’L PANEL OF EXPERTS IN INT’L HUMAN RIGHTS LAW AND ON SEXUAL ORIENTATION AND GENDER IDENTITY, *THE YOGYAKARTA PRINCIPLES: PRINCIPLES ON THE APPLICATION OF INTERNATIONAL HUMAN RIGHTS LAW IN RELATION TO SEXUAL ORIENTATION AND GENDER IDENTITY* (2007), [http://yogyakartaprinciples.org/wp-content/uploads/2016/08/principles\\_en.pdf](http://yogyakartaprinciples.org/wp-content/uploads/2016/08/principles_en.pdf) [hereinafter *YOGYAKARTA PRINCIPLES*].

87 SECOND INT’L PANEL OF EXPERTS IN INT’L HUMAN RIGHTS LAW, *SEXUAL ORIENTATION, GENDER IDENTITY, GENDER EXPRESSION AND SEX CHARACTERISTICS, THE YOGYAKARTA PRINCIPLES PLUS 10* (2017), [http://yogyakartaprinciples.org/wp-content/uploads/2017/11/A5\\_yogyakartaWEB-2.pdf](http://yogyakartaprinciples.org/wp-content/uploads/2017/11/A5_yogyakartaWEB-2.pdf) [hereinafter *YOGYAKARTA PRINCIPLES PLUS 10*].

88 *Id.* at 4.

89 *YOGYAKARTA PRINCIPLES*, *supra* note 86, at 8.

sexual orientations and gender identities are entitled to the full enjoyment of all human rights.”<sup>90</sup> Principle 3 notes, “Each person’s self-defined sexual orientation and gender identity is integral to their personality and is one of the most basic aspects of self-determination, dignity and freedom.”<sup>91</sup> Principle 9 addresses deprivation of liberty and, in that context, provides that “[e]veryone deprived of liberty shall be treated with humanity and with respect for the inherent dignity of the human person.”<sup>92</sup> In this regard, Principle 9 specifically provides that “[s]exual orientation and gender identity are integral to each person’s dignity.”<sup>93</sup> The Yogyakarta Principles plus 10, at Principle 35, which addresses the Right to Sanitation, makes clear that states are obligated to “[e]nsure that there are adequate public sanitation facilities which can be accessed safely and with dignity by all persons regardless of their sexual orientation, gender identity, gender expression or sex characteristics.”<sup>94</sup>

This brief discussion on the protections found in numerous human rights instruments underscores the importance of dignity to the fulfillment of human rights. These international documents not only protect dignity, they center dignity. All recognize dignity as innate and thus inalienable—a sphere in which the state cannot intrude. Significant for this project is not only the nature of dignity as inherent in the human person, but also its role in underscoring and elucidating the indivisibility of civil and political rights, on the one hand, and economic, social, and cultural rights on the other. This foundational international framework facilitates and frames an examination of dignity with respect to domestic law.

### ***C. The Legal Foundations of Dignity – U.S. Law***

Because the symposium focused on international law and local justice, it is appropriate to turn to a “local justice” component—the U.S. Constitution—to examine its foundations in and protections of dignity. Significantly, textually, the Constitution does not mention the word *dignity* a single time. Now, to be sure, the document is older than the more recent international texts. Nonetheless, at least for originalists and textualists, there

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90 *Id.* at 10.

91 *Id.* at 11.

92 *Id.* at 16.

93 *Id.*

94 YOGYAKARTA PRINCIPLES PLUS 10, *supra* note 87, at 12.

is no right to dignity in the U.S. Constitution. This is significant because as recently as 2015, two Supreme Court justices, Chief Justice Roberts and Justice Thomas, dissented from expanding the fundamental right of marriage<sup>95</sup> to couples of the same sex on dignity grounds because “[t]here is . . . no . . . ‘Nobility and Dignity’ Clause in the Constitution.”<sup>96</sup> Others, including the *Obergefell* majority, differ, and find dignity in the liberty clause of the Fifth and Fourteenth Amendments.<sup>97</sup> These interpretations have support in decisions of the Supreme Court dating to the late 1700s.<sup>98</sup>

Before engaging the historical development of dignitarian rights in U.S. jurisprudence, it should be noted that the Constitution’s Supremacy Clause<sup>99</sup> also provides a means to include dignity in U.S. law. The Supremacy Clause provides, among other things, “Treaties made . . . under the authority of the United States, shall be the supreme Law of the Land; and the Judges in every state shall be bound thereby . . . .”<sup>100</sup> Given that the U.S. has ratified the ICCPR,<sup>101</sup> and that the ICCPR recognizes that human “rights derive from the inherent dignity of the human person,”<sup>102</sup> it can be argued that there indeed exists a basis for a constitutional claim of dignity, especially if we take an incorporationist approach.<sup>103</sup> However, the doctrine of non-self-executing treaties, which provides that, unless there is implementing legislation, the international source cannot be used as a basis for a claim in the courts of the U.S.,<sup>104</sup> would impede using the ICCPR for such purposes. Congress has not passed implementing legislation.

95 *Loving v. Virginia*, 388 U.S. 1, 12 (1967).

96 *Obergefell v. Hodges*, 135 S. Ct. 2584, 2616 (2015) (Roberts, J., dissenting).

97 *Id.* at 2593–608 (2015) (mentioning *dignity* nine times).

98 *See, e.g.*, *Chisholm v. Georgia*, 2 U.S. 419, 455 (1793).

99 U.S. CONST. art. VI.

100 *Id.*

101 *Status of Ratification Interactive Dashboard*, OFFICE OF THE UNITED NATIONS HIGH COMM’R FOR HUMAN RIGHTS, <http://indicators.ohchr.org/> (last visited Apr. 18, 2018).

102 ICCPR, *supra* note 22, pmbl.

103 An incorporationist approach is one in which treaties are automatically incorporated to U.S. law based on the Supremacy Clause. *International Law and Municipal Law*, ENCYCLOPAEDIA BRITANNICA, <https://www.britannica.com/topic/international-law/International-law-and-municipal-law> (last visited Aug. 1, 2018).

104 *See* BARRY E. CARTER & ALLEN S. WEINER, *INTERNATIONAL LAW* 164–65 (6th ed. 2011).



Notwithstanding the absence of the word *dignity* in the Constitution, case law provides us interpretive moves that effectively constitutionalize dignitarian rights. In 1793, the Supreme Court stated that from the “native dignity” of man, “a state derives all its acquired importance.”<sup>105</sup> The Court’s language suggests that a person cannot surrender dignity; dignity is inherent in humanity.

However, because of the structure of society at the time, only a small portion of the U.S. population enjoyed this natural dignity. *Williams v. Ash*,<sup>106</sup> an 1843 case, is instructive as to the skewed cultural and social perceptions of who enjoyed the dignity inherent in all humanity. *Ash* presented the Supreme Court with an argument that a slave, once free, acquired a “higher dignity.”<sup>107</sup> The Court, however, did not even address the dignity argument.<sup>108</sup> In an opinion written by Chief Justice Taney, the Court ruled that, based on the language of the will, Mr. Ash became a free man at the moment he was sold.<sup>109</sup> Thus, the slave gained his freedom because he, a piece of property, was sold and the will provided that, upon that condition, freedom would ensue.

Merely 12 years after his opinion in *Ash*, Justice Taney made clear that slaves did not have dignitarian rights. In *Dred Scott v. Sandford*,<sup>110</sup> the Chief Justice confirmed that the “enslaved African

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105 *Chisholm v. Georgia*, 2 U.S. 419, 455 (1793).

106 *Williams v. Ash*, 42 U.S. 1 (1843). The case dealt with the validity of a will provision in which the grantor, who bequeathed slaves to her nephew, stated that if the nephew sold the slaves or carried them outside of Maryland, the slaves would be freed for life. *Id.* at 2. When the nephew sold Mr. Ash, the slave’s lawyer filed a petition for freedom. *Id.* The court instructed the jury that the slave became free at the moment of sale. *Id.* at 3. The nephew sought to invalidate the provision as “repugnant to the nature of the estate, and therefore void.” *Id.* at 4. The argument before the Supreme Court was that slaves were property in the same way as any other chattel. *Id.* at 4–5. Mr. Ash’s counsel argued that the will’s language was enforceable and that someone cannot own a person in the same manner in which they own chattel. *Id.* at 5–9. Mr. Ash’s counsel posed the question of whether a slave can be property at all. *Id.* at 9. He argued that as human beings, slaves possess intangibles that no one other than themselves can claim a right in, such as “a reasoning faculty, a conscience, [and] an immortal spirit.” *Id.*

107 *Id.* at 9.

108 *Id.* at 12–14.

109 *Id.* at 14.

110 *Dred Scott v. Sandford*, 60 U.S. 393 (1857). Scott was a slave who, because of his owner’s moves, resided in a free state (Illinois) and territory (Wisconsin). *Id.* at 493 (Campbell, J., concurring). When Scott and his owner returned to



race” was not entitled to equality.<sup>111</sup> Rather, the Court concluded that slaves are property without citizenship rights and did not have the right to sue.<sup>112</sup> In its decision, the Court invalidated the Missouri Compromise, legislation in which Congress had allowed Missouri to join the Union as a slave state but forbid slavery in the rest of the Louisiana Purchase.<sup>113</sup> Neither the word nor the concept of dignity was part of the decision.<sup>114</sup>

The next mention of dignity in a Supreme Court opinion was in Justice Field’s dissent in *Brown v. Walker*,<sup>115</sup> a case involving the Fifth Amendment.<sup>116</sup> Justice Field noted that the roots of the Fifth Amendment were “personal self-respect, liberty, independence, and dignity.”<sup>117</sup> Justice Field observed that governments have sacrificed many conveniences and capabilities to protect individual dignity and argued that the majority’s holding was an affront to that constitutional value.<sup>118</sup>

Sixty years after *Brown v. Walker*, in the plurality opinion in *Trop v. Dulles*,<sup>119</sup> Chief Justice Warren declared that “[t]he basic concept underlying the Eighth Amendment is nothing less than the dignity of man.”<sup>120</sup> In *Furman v. Georgia*,<sup>121</sup> a 1972 case concerning whether the death penalty constitutes cruel and unusual punishment, Justice Brennan’s concurrence framed the issue in dignitarian terms.<sup>122</sup> Justice Brennan asked “whether the deliberate infliction of death is today consistent with the command of the Clause that the State may not inflict punishments that do not

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Missouri, a slave state, Scott sued for his freedom, arguing that residence in a free state and territory entitled him to freedom. *Id.* at 394.

111 *Id.* at 410.

112 *Id.* at 427.

113 *Id.* at 432.

114 *Id. passim.*

115 *Brown v. Walker*, 161 U.S. 591 (1896)

116 *Id.* at 593–94. The Court held that because the statute provided absolute immunity against future prosecution for the witness, the witness could be compelled to testify. *Id.* at 610.

117 *Id.* at 632.

118 *Id.*

119 *Trop v. Dulles*, 356 U.S. 86 (1958).

120 *Id.* at 100.

121 *Furman v. Georgia*, 408 U.S. 238 (1972). The per curiam opinion was narrow in scope, holding that imposing a death penalty in the instances presented in the case would constitute cruel and unusual punishment and violate the Eighth and Fourteenth Amendments to the Constitution. *Id.* at 239–40 (per curiam).

122 *Id.* at 269–306 (Brennan, J., concurring).

comport with human dignity.”<sup>123</sup> He articulated four principles to ascertain constitutionality under the Eighth Amendment, the first of which provides that “a punishment must not be so severe as to be degrading to the dignity of human beings.”<sup>124</sup>

Four years after *Furman*, Justice Stevens’s dissenting opinion in *Meachum v. Fano*<sup>125</sup> invoked dignity as a constitutional value grounded in the liberty interest found in the Constitution.<sup>126</sup> *Meachum* was an action brought by state prisoners alleging deprivation of liberty without due process when the state transferred them to less favorable prisons without first having a fact-finding hearing.<sup>127</sup> Evoking the institution of slavery by noting that prisoners were once considered “the slave[s] of the State,” Justice Stevens faulted the majority’s ruling because, from his perspective, failing to recognize a liberty interest contradicts the “right to be treated with dignity—which the Constitution may never ignore.”<sup>128</sup>

More recently, Justice Brennan’s dignitarian arguments have found favor in Justice Kennedy’s opinions—opinions that show he embraces dignity as a constitutional value. For example, Justice Kennedy wrote for the majority in a case holding that the Eighth and Fourteenth Amendments prohibit the execution of individuals under the age of majority at the time of their crimes.<sup>129</sup> Justice Kennedy explains, “By protecting even those convicted of heinous crimes, the Eighth Amendment reaffirms the duty of the government to respect the dignity of all persons.”<sup>130</sup>

#### **D. Dignity and Democracy**

In contemporary history, the cases that focus on LGBT rights showcase Justice Kennedy’s embrace of dignity as a

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123 *Id.* at 285. According to Justice Brennan, it was irrelevant that the Court had previously decided cases regarding the death penalty and assumed that death as a form of punishment was allowable under the Constitution: “The constitutionality of death itself under the Cruel and Unusual Punishments Clause is before this Court for the first time; we cannot avoid the question by recalling past cases that never directly considered it.” *Id.*

124 *Id.* at 271.

125 *Meachum v. Fano*, 427 U.S. 215 (1976).

126 *Id.* at 233.

127 *Id.* at 216.

128 *Id.* at 231, 233.

129 *Roper v. Simmons*, 543 U.S. 551, 578 (2005).

130 *Id.* at 560.

constitutional value. The line of cases that developed LGBT rights also unveiled the potential failings of democracy. Specifically, the conflict between dignity and democracy arises in circumstances in which the people—either directly or by their elected representatives—have spoken with respect to the desire to deny the existence of certain rights for the LGBT population. Yet, harking to philosopher Louis Blanc’s observations,<sup>131</sup> perhaps democracy should not be the basis for deciding certain rights. Blanc, for example, observed that certain rights should not depend on the will of the majority; he wrote that freedom of the press, freedom of conscience, freedom of association, the right of assembly, and the right to subsist by working shall not depend on a vote of the majority.<sup>132</sup>

The 1986 opinion in *Bowers v. Hardwick*,<sup>133</sup> a case considered before Justice Kennedy was on the bench, was decided by a slim 5–4 majority.<sup>134</sup> *Bowers* reveals how a majoritarian democratic approach, viewed through the lens of the targeted minority, can easily be the tyranny of the majority. Such tyranny can, and often does, constitute an affront to dignity. After framing the issue as “whether the Federal Constitution confers a fundamental right upon homosexuals to engage in sodomy,”<sup>135</sup> the *Bowers* Court concluded that the state could constitutionally criminalize consensual same-sex intimacy between adults.<sup>136</sup> Consenting adults could not engage in sexual conduct in the privacy of their home; the state could regulate homosexual conduct. The only mention of dignity was in Justice Blackmun’s dissent—a dissent in which he states what the case is really about: liberty—“the most comprehensive of rights and the right most valued by civilized men, namely, the right to be let alone.”<sup>137</sup> Next, noting the majoritarian bias in the liberty interest of privacy, Justice Stevens explained, “[E]very free citizen has the same interest in ‘liberty’

131 See LOUIS BLANC, *DU SUFFRAGE UNIVERSEL* (1850), reprinted in *QUESTIONS D’AUJOURD’HUI ET DE DEMAIN* 201 (E. Dentu ed., 1873); *DE LA REPRÉSENTATION PROPORTIONNELLE DES MINORITÉS* (1864), reprinted in *QUESTIONS D’AUJOURD’HUI ET DE DEMAIN* 239 (E. Dentu ed., 1873).

132 *DU SUFFRAGE UNIVERSEL*, *supra* note 131, at 237–38.

133 *Bowers v. Hardwick*, 478 U.S. 186 (1986).

134 *Id.*

135 *Id.* at 190.

136 *Id.*

137 *Id.* at 199 (internal quotations omitted) (Blackmun, J., dissenting).

that the members of the majority share.”<sup>138</sup> The majority should not have denied dignity to LGBT persons, but they indeed did so.

Ten years after *Bowers*, the Court decided *Romer v. Evans*,<sup>139</sup> the first case in which the Court found unconstitutional discrimination against LGBT persons. The plaintiffs challenged an amendment to the Colorado Constitution that prohibited the State, cities, and towns from enacting laws or ordinances to protect LGBT persons from discrimination based on sexual orientation.<sup>140</sup> The majority opinion, written by Justice Kennedy, effectively upheld LGBT dignity rights. However, it did so without using the word *dignity*. Rather, the Court found that the challenged discrimination had to fail; it failed the rational basis test; it was unconstitutional for the Constitution “neither knows nor tolerates classes among citizens.”<sup>141</sup> This ruling affirmed the judgment of the Colorado Supreme Court, which had also invalidated the discriminatory law in question, although on different grounds.<sup>142</sup> The Colorado Court held that the law infringed on the fundamental right of gays and lesbians to participate in the political process.<sup>143</sup> Thus, democratically enacted state laws, passed by the majority of the population, still fail constitutional scrutiny if they discriminate based on animus against a particular segment of the population.<sup>144</sup> The majority cannot deny a minority their inherent dignity by denying the indicated minority their rights.

In 2003, the Supreme Court decided *Lawrence v. Texas*,<sup>145</sup> a significant case that reaffirmed *Romer*’s equality and democracy message—the equal rights of all persons under the constitution<sup>146</sup>—and explicitly overturned *Bowers*<sup>147</sup> (over a

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138 *Id.* at 218.

139 *Romer v. Evans*, 517 U.S. 620 (1996).

140 *Id.* at 624.

141 *Id.* at 623 (quoting *Plessy v. Ferguson*, 163 U. S. 537, 559 (1896) (dissenting opinion)).

142 *Id.* at 626.

143 *Evans v. Romer*, 854 P.2d 1270, 1286 (Colo. 1993).

144 *Romer*, 517 U.S. at 632. The Court explained why the Colorado Amendment had to fail: “First, the amendment has the peculiar property of imposing a broad and undifferentiated disability on a single named group, an exceptional and, as we shall explain, invalid form of legislation. Second, its sheer breadth is so discontinuous with the reasons offered for it that the amendment seems inexplicable by anything but animus toward the class it affects.” *Id.*

145 *Lawrence v. Texas*, 539 U.S. 558 (2003).

146 *See id.*

147 *Id.* at 578.

vehement and scathing dissent by Justice Scalia).<sup>148</sup> The Court invalidated a Texas law that made it a crime for persons of the same sex to engage in intimate sexual conduct as violating the liberty and privacy interests protected by the Due Process Clause of the Fourteenth Amendment.<sup>149</sup> The absence of the word *dignity* in the constitutional text notwithstanding, the Court, in a 6–3 decision written by Justice Kennedy, held that the plaintiffs have the right to the respect and dignity to which all human beings are entitled.<sup>150</sup> The Court even referred to the European Court of Human Rights’ dignity-based cases, which had held that the state had no business interfering with intimate, private, consensual conduct between adults.<sup>151</sup>

Because the Texas restriction referred to intimate conduct, the Court said there had to be particularly serious reasons for interference.<sup>152</sup> The Court ruled that the reality that many members of civil society, including families, workplaces, educational spaces, and religious institutions, consider homosexual conduct immoral and sinful, and may be shocked, offended, or disturbed by the commission of others’ private homosexual acts simply cannot be legal justification for the prohibition of those acts.<sup>153</sup> Quoting from Justice Stevens’s dissent in *Bowers*, the Court clearly stated that “the fact that the governing majority in a State has traditionally viewed a particular practice as immoral is not a sufficient reason for upholding a law prohibiting the practice.”<sup>154</sup> Such justification would be antidemocratic.<sup>155</sup>

Interestingly, Justice O’Connor, while agreeing with the Court’s outcome on the unconstitutionality of the Texas law, analyzed it differently. Rather than overturn *Bowers*, she engaged in an equal protection analysis.<sup>156</sup> Even in this context, however, she found that although “the Constitution presumes that even improvident decisions will eventually be rectified by the democratic processes[,]’ [w]e have consistently held, however, that some objectives, such as ‘a bare . . . desire to harm a politically unpopular

148 *See id.* at 586–605 (Scalia, J., dissenting).

149 *Id.* at 578 (majority opinion).

150 *See id.* The Court used the word *dignity* three times. *Id.* at 567, 574–75.

151 *Id.* at 573, 576.

152 *Id.* at 567.

153 *See id.* at 577–78.

154 *Id.* at 577.

155 *Id.*

156 *Id.* at 579–85 (O’Connor, J., concurring).

group,' are not legitimate state interests."<sup>157</sup> With respect to the substantive due process analysis, she would have deferred to the majority's views in *Bowers*, notwithstanding their discriminatory nature.<sup>158</sup>

Ten years later, the Court decided *United States v. Windsor*,<sup>159</sup> in which we see the explosion of an explicit recognition of dignity as a constitutional value. This case challenged the provisions of a federal law, the Defense of Marriage Act (DOMA), which provided that marriage is an institution that exists to protect the relationship between one man and one woman.<sup>160</sup> The consequence of the law was to deny the over 1,000 federal benefits of marriage to couples of the same sex, regardless of whether the state in which they resided recognized such unions.<sup>161</sup>

Interestingly, the facts of the case were hugely compelling. Edith Windsor was the widow of Thea Spyer.<sup>162</sup> The couple, who had been together since 1963,<sup>163</sup> were New York residents who in 2007 had married in Canada, a country that recognized marriage between persons of the same sex.<sup>164</sup> They lived in New York, a state that accepted the validity of their marriage.<sup>165</sup> When Spyer died, she left her estate to Windsor.<sup>166</sup> Because the federal law (DOMA) did not recognize their marriage, the government sought \$363,000 in estate taxes from Windsor.<sup>167</sup> Had the government recognized their marriage, Windsor would not have had to pay any taxes, as she would have qualified for the marital exemption.<sup>168</sup> Windsor paid the taxes but requested a refund, which the federal government

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157 *Id.* at 579–80 (citations omitted).

158 *Id.* at 579.

159 *United States v. Windsor*, 133 S. Ct. 2675 (2013).

160 *Id.* at 2682; Defense of Marriage Act (DOMA), 1 U.S.C. § 7 (2012), *invalidated by United States v. Windsor*, 133 S. Ct. 2675 (2013), 28 U.S.C. § 1738C, *called into question by Obergefell v. Hodges*, 135 S. Ct. 2584 (2015).

161 OFFICE OF THE GEN. COUNSEL, U.S. GEN. ACCOUNTING OFFICE, GAO/OGC-97-16, DEFENSE OF MARRIAGE ACT 1–2 (1997). *See also* OFFICE OF THE GEN. COUNSEL, U.S. GEN. ACCOUNTING OFFICE, GAO-04-353R, DEFENSE OF MARRIAGE ACT: UPDATE TO PRIOR REPORT (2004).

162 *Windsor*, 133 S. Ct. at 2682.

163 *Id.* at 2683.

164 *Id.* at 2682.

165 *Id.* at 2683.

166 *Id.* at 2682.

167 *Id.* at 2683.

168 *Id.*

denied.<sup>169</sup> Windsor then sued to obtain a declaration from the federal district court that DOMA effected an unconstitutional denial of the equal protection of the laws guaranteed by the Fifth Amendment.<sup>170</sup> The district court agreed with her, and the Second Circuit affirmed the district court's decision.<sup>171</sup>

The case then went to the Supreme Court. The issue the Court addressed was whether DOMA's definition of marriage, for purposes of federal law, as the "legal union between one man and one woman" denied the equal protection of the laws, guaranteed under the Fifth Amendment, to couples of the same sex whose marriage is legal under their state's laws.<sup>172</sup> The Court concluded, in a 5–4 decision, that DOMA's definition of marriage violated the Constitution.<sup>173</sup>

The majority decision by Justice Kennedy, agreeing with Windsor's position, was fully dignity-based. Justice Kennedy used the word *dignity* ten times,<sup>174</sup> noting the "status and dignity" that attaches to marriage,<sup>175</sup> and stating that the essence of DOMA was the interference with the "equal dignity" of same-sex marriages.<sup>176</sup> Thus, notwithstanding the history and tradition of denying couples of the same sex access to the state-sanctioned institution of marriage, and the congressional support for DOMA, the Court elevated dignitarian interests to a constitutional level that mandated the recognition of the bond between Windsor and Spyer. Equality trumps democracy, especially when democracy promotes inequality and subordination.

This conclusion was, as noted above, not unanimous. In fact, Justice Scalia's scathing dissent focuses on how democracy—a majority's mandate—is the only tool to resolve the debate. Rejecting the majority's analysis, Justice Scalia noted in the opening paragraph of his dissent that "we have no power under the Constitution to invalidate this democratically adopted legislation."<sup>177</sup> He observed further, "Since DOMA's passage,

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169 *Id.*

170 *Id.*

171 *See id.* at 2682.

172 *Id.* at 2683–84.

173 *Id.* at 2696.

174 *Id.* at 2689–96 (including one instance in which Justice Kennedy used the word *indignity*).

175 *Id.* at 2689.

176 *Id.* at 2693.

177 *Id.* at 2697–98 (Scalia, J., dissenting).



citizens on all sides of the question have seen victories and they have seen defeats. There have been plebiscites, legislation, persuasion, and loud voices—in other words, democracy.”<sup>178</sup> In other words, Justice Scalia would allow majoritarian voices to deny equality and dignity; he would allow, contrary to Federalist Papers ideals,<sup>179</sup> the enactment of the tyranny of the majority.<sup>180</sup>

A mere two years after *Windsor*, the Court directly confronted the marriage equality question in *Obergefell v. Hodges*.<sup>181</sup> The *Obergefell* decision consolidated six cases from Michigan, Kentucky, Ohio and Tennessee—all states that defined marriage as between one man and one woman.<sup>182</sup> The petitioners were 14 couples of the same sex and two individuals whose partners of the same sex had passed away.<sup>183</sup> They claimed that their states denied them the equal protection of the laws by denying them the right to marry or by refusing to recognize a legal marriage performed in another state.<sup>184</sup>

The Court, before engaging the law on marriage, addressed the history of marriage, which “reveal[s] the transcendent importance of marriage.”<sup>185</sup> In addressing this history, the Court, while recognizing that traditionally marriage has been a heterosexual union, immediately used dignitarian values in its analysis, noting that marriage “has promised nobility and dignity to all persons, without regard to their station in life.”<sup>186</sup> Justice Kennedy wrote the majority opinion and used the word *dignity* nine times.<sup>187</sup> The literal basis of the right to dignity, the Court

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178 *Id.* at 2710.

179 THE FEDERALIST NO. 51 (James Madison) (discussing two methods of providing against the “evil” of “a majority . . . united by a common interest, [that would signify that] the rights of the minority will be insecure” and noting with respect to the second method that “[w]hilst all authority in it will be derived from and dependent on the society, the society itself will be broken into so many parts, interests, and classes of citizens, that the rights of individuals, or of the minority, will be in little danger from interested combinations of the majority.”).

180 Alexis de Tocqueville first coined the phrase “tyranny of the majority.” ALEXIS DE TOCQUEVILLE, DEMOCRACY IN AMERICA 280 (1835–1840); see also JOHN STUART MILL, ON LIBERTY (1859).

181 *Obergefell v. Hodges*, 135 S. Ct. 2584 (2015).

182 *Id.* at 2593.

183 *Id.*

184 *Id.*

185 *Id.* at 2594.

186 *Id.*

187 *Id.* at 2593–608.

observed, is the liberty interest expressly granted by the Due Process Clause.<sup>188</sup> In the end, the majority, citing de Tocqueville by referring to marriage as “a keystone of our social order,” concluded that the state cannot deny couples of the same sex the fundamental right to marry.<sup>189</sup>

Significantly, the majority rejected Chief Justice Roberts’s appeal to be cautious in the approach to granting this fundamental right to same-sex couples.<sup>190</sup> It did not take the lure of the warning that “there has been insufficient democratic discourse before deciding an issue so basic as the definition of marriage.”<sup>191</sup> Rather, the Court squarely faced the democracy question, and, while it acknowledged that “democracy is the appropriate process for change,”<sup>192</sup> it articulated an outcome-determinative caveat: “so long as that process does not abridge fundamental rights.”<sup>193</sup> Thus, the Court explicitly rejected the tyranny of the majority.

To be sure, the word *dignity* appeared 30 times in the opinion, but not all of the uses of the word *dignity* were celebratory. In fact, out of the 30 uses of the word, the dissenting justices used *dignity* 20 times—three times by Chief Justice Roberts and 17 times by Justice Thomas. Chief Justice Roberts, for example, chidingly noted the absence of a “‘Nobility and Dignity’ Clause in the Constitution” and disagreed with the majority finding such a right in the Due Process Clause.<sup>194</sup> Moreover, in questioning the reach of dignitarian rights, he twice used the word, as he questioned why such dignity would not similarly attach to plural marriages.<sup>195</sup> Most significant, much like Justice Scalia in *Windsor*, Chief Justice Roberts insisted that the proper vehicle to effect change in the definition of marriage in civil society is “the people,” through the democratic process.<sup>196</sup> That determination by the people, the Chief

188 *Id.* at 2597.

189 *Id.* at 2601, 2604–05 (specifically reaching “the conclusion that the right to marry is a fundamental right inherent in the liberty of the person, and under the Due Process and Equal Protection Clauses of the Fourteenth Amendment couples of the same-sex may not be deprived of that right and that liberty. The Court now holds that same-sex couples may exercise the fundamental right to marry. No longer may this liberty be denied to them.”).

190 *See id.* at 2612 (Roberts, C.J., dissenting).

191 *Id.* at 2605 (majority opinion).

192 *Id.*

193 *Id.*

194 *Id.* at 2616 (Roberts, C.J., dissenting).

195 *Id.* at 2621–22.

196 *Id.*

Justice concluded, is the only “process due the people on issues of this sort—the democratic process.”<sup>197</sup>

Justice Scalia’s dissent joined the Chief Justice’s and called the case outcome a “threat to American democracy.”<sup>198</sup> Again, Justice Scalia seemed to embrace democracy over fundamental rights. This stance elucidates the potential failings of democracy for numerical minorities, even when faced with possible denial of established fundamental rights.

Similarly, Justice Thomas decried the decision as a deviation from the normal democratic process.<sup>199</sup> Moreover, he used the word *dignity* 17 times, both to note that dignity is innate, and thus the government cannot bestow dignity, as well as to observe that “the Constitution contains no ‘dignity’ Clause.”<sup>200</sup> Indeed, he even posed that neither slavery nor internment could rob a person of dignity, concluding that “[t]he government cannot bestow dignity, and it cannot take it away.”<sup>201</sup> Like Justice Scalia and Chief Justice Roberts, Justice Thomas would let the tyranny of the majority, if expressed through the democratic process, prevail over the exercise of fundamental rights by LGBT persons.

Significantly, the Court upheld dignitarian rights in light of interesting democracy statistics. In 2015, when *Obergefell* was before the Court and yet to be decided, 37 states had legal marriage between persons of the same sex.<sup>202</sup> However, only eight states legalized same-sex marriage by legislative action<sup>203</sup> and only three did so by popular vote<sup>204</sup>—meeting the standards of those who insist that the democratic process is the only way to change history, culture, and/or law. The other 26 states had legal marriage between persons of the same sex due to court decision.<sup>205</sup> The

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197 *Id.*

198 *Id.* at 2626 (Scalia, J., dissenting).

199 *Id.* at 2631.

200 *Id.* at 2639.

201 *Id.*

202 *State-by-State History of Banning and Legalizing Gay Marriage, 1994–2015*, PROCON.ORG, <https://gaymarriage.procon.org/view.resource.php?resourceID=004857> (last updated Feb. 16, 2016, 1:44 PM).

203 Eight by state legislature: Delaware (July 1, 2013), Hawaii (Dec. 2, 2013), Illinois (June 1, 2014), Minnesota (Aug. 1, 2013), New Hampshire (Jan. 1, 2010), New York (July 24, 2011), Rhode Island (Aug. 1, 2013), Vermont (Sep. 1, 2009). *Id.*

204 Three by popular vote: Maine (Dec. 29, 2012), Maryland (Jan. 1, 2013), Washington (Dec. 9, 2012). *Id.*

205 Twenty-six by court decision: Alabama (Feb. 9, 2015), Alaska (Oct. 17,

remaining 13 states banned marriages between people of the same sex—12 by constitutional amendment and state law<sup>206</sup> and one by constitutional amendment only.<sup>207</sup> In addition to the 13 states that had expressly denied the right to same-sex marriage through the legislative process, 26 had done the same, but their state courts had already invalidated state laws prohibiting marriage between people of the same sex. Thus, were the democratic process the only mechanism to grant the fundamental right to marriage for couples of the same sex, only 11 states would have provided equal access to marriage. Fortunately, the majority of the Court did not see fit to instantiate the tyranny of the majority by elevating the democratic process over fundamental rights.

Thus, in *Obergefell*, dignity prevailed notwithstanding the majoritarian will to deny marriage to couples of the same sex and notwithstanding the dissenters' mocking use of the majority's framework. Given the tensions evident in not only *Obergefell* but also in the cases that preceded it, it is not surprising that there are some very telling and disturbing post-*Obergefell* developments—disturbing because the cases and legislation reflect a backlash to the explosion of dignity.

In the summer of 2017, in *Pavan v. Smith*,<sup>208</sup> the Court considered whether Arkansas's refusal to put a non-birth mother's name on the birth certificate could withstand constitutional challenge.<sup>209</sup> The Court in a *per curiam* opinion stated, “[T]he Constitution entitles same-sex couples to civil marriage ‘on the

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2014), Arizona (Oct. 17, 2014), California (June 28, 2013), Colorado (Oct. 7, 2014), Connecticut (Nov. 12, 2008), Florida (Jan. 6, 2015), Idaho (Oct. 13, 2014), Indiana (Oct. 6, 2014), Iowa (Apr. 24, 2009), Kansas (Nov. 12, 2014), Massachusetts (May 17, 2004), Montana (Nov. 19, 2014), Nevada (Oct. 9, 2014), New Jersey (Oct. 21, 2013), New Mexico (Dec. 19, 2013), North Carolina (Oct. 10, 2014), Oklahoma (Oct. 6, 2014), Oregon (May 19, 2014), Pennsylvania (May 20, 2014), South Carolina (Nov. 20, 2014), Utah (Oct. 6, 2014), Virginia (Oct. 6, 2014), West Virginia (Oct. 9, 2014), Wisconsin (Oct. 6, 2014), Wyoming (Oct. 21, 2014). *Id.*

206 Twelve by constitutional amendment and state law: Arkansas (2004, 1997), Georgia (2004, 1996), Kentucky (2004, 1998), Louisiana (2004, 1999), Michigan (2004, 1996), Mississippi (2004, 1997), Missouri (2004, 1996), North Dakota (2004, 1997), Ohio (2004, 2004), South Dakota (2006, 1996), Tennessee (2006, 1996), Texas (2005, 1997). *Id.*

207 One by constitutional amendment only: Nebraska (2000). *Id.*

208 *Pavan v. Smith*, 137 S. Ct. 2075 (2017).

209 *Id.* at 2075.

same terms and conditions as opposite-sex couples.”<sup>210</sup> The Arkansas birth certificate law treated couples of the same sex differently and thus “infringe[d] *Obergefell*’s commitment to provide same-sex couples ‘the constellation of benefits that the States have linked to marriage . . . .’”<sup>211</sup> Thus, dignity prevailed over discriminatory legislation.

But, somewhat ironically, from the state that brought *Lawrence*, four days after *Pavan*, the Texas Supreme Court ruled in *Pidgeon v. Turner*<sup>212</sup> that the *Obergefell* decision from the U.S. Supreme Court, which legally recognized same-sex marriages, did not determine whether same-sex married couples are entitled to the same spousal benefits of opposite-sex married couples.<sup>213</sup> The litigants brought the case as a taxpayers’ claim—they did not want their tax money to pay for spousal benefits for same-sex married couples.<sup>214</sup> Noting that Texas law provides that marriage is between one man and one woman, they claimed that although Texas may have to give marriage licenses, it need do no more.<sup>215</sup>

To the contrary, the city of Houston insisted that *Obergefell* clearly concluded that the state must provide any rights or benefits attached to marriage equally to all married couples, straight or gay.<sup>216</sup> *Pavan* would seem to support this perspective. However, on December 4, 2017, the Supreme Court denied Houston’s petition for a writ of certiorari for the review of the state court’s ruling.<sup>217</sup> Indeed, the Texas Supreme Court sent the case to the lower court for a decision on whether the lawsuit has merit in light of *Obergefell* and *Pavan*.<sup>218</sup> The question of whether dignity prevails over the tyranny of the majority seems yet to be fully resolved.

### **E. Dignity and Inequality**

Neither in the U.S. nor abroad are LGBT citizens enjoying the plethora of rights that combine to enable the enjoyment

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210 *Id.* at 2076.

211 *Id.*

212 *Pidgeon v. Turner*, 538 S.W.3d 73, 80 (Tex.) cert. denied, 138 S. Ct. 505 (2017). The case was originally filed as *Pidgeon v. Parker*, reflecting the then-mayor of Houston, Annise Parker. *See id.* at 78.

213 *Id.* at 85–86.

214 *Id.* at 78–79.

215 *Id.* at 79.

216 *Id.* at 86.

217 *Id.*, cert. denied, 138 S. Ct. 505 (2017).

218 *Id.* at 89.

of dignity. There exist places around the world where simply being gay may result in the death penalty.<sup>219</sup> Other places are re-criminalizing gay conduct.<sup>220</sup>

Although 122 U.N. members, plus Taiwan and Kosovo, do not criminalize sexual conduct between adults of the same sex, many national and municipal laws around the world do.<sup>221</sup> One salient entity in the backlash against dignity for the LGBT community is the Alliance Defending Freedom (ADF), a Christian, conservative, pro-life, non-profit group with far-reaching national and international connections.<sup>222</sup> ADF is not only active in the U.S., promoting anti-LGBT legislation and bringing cases to reduce the rights of LGBT people,<sup>223</sup> but is also exporting its policies abroad.<sup>224</sup> In fact, ADF is responsible for promoting and successfully passing laws abroad that criminalize homosexuality.<sup>225</sup>

There are 72 countries in which homosexual acts are illegal.<sup>226</sup> In 45 of these countries, the laws extend to women

219 Berta Esperanza Hernández-Truyol, *La Juventud y las Familias LGBTI como Poblaciones Vulnerables: Mito y Realidad de las Protecciones Legales*, in *ORIENTAMENTO SESSUALE, IDENTITÀ DI GENERE E TUTELA DEI MINORI* 31, 43 (Berta Esperanza Hernández-Truyol & Roberto Virzo eds., 2016).

220 *Id.* at 42–45.

221 AENGUS CARROLL & LUCAS RAMÓN MENDOS, INTERNATIONAL LESBIAN, GAY, BISEXUAL, TRANS AND INTERSEX ASSOCIATION, STATE SPONSORED HOMOPHOBIA (12th ed. 2017), [http://ilga.org/downloads/2017/ILGA\\_State\\_Sponsored\\_Homophobia\\_2017\\_WEB.pdf](http://ilga.org/downloads/2017/ILGA_State_Sponsored_Homophobia_2017_WEB.pdf) [hereinafter ILGA].

222 *Who We Are*, ALL. DEFENDING FREEDOM, <https://www.adflegal.org/about-us> (last visited Apr. 19, 2018); see also Sarah Posner, *The Christian Legal Army Behind ‘Masterpiece Cakeshop,’* THE NATION (Nov. 28, 2017), <https://www.thenation.com/article/the-christian-legal-army-behind-masterpiece-cakeshop/>.

223 Posner, *supra* note 222; *Alliance Defending Freedom*, S. POVERTY LAW CTR., <https://www.splcenter.org/fighting-hate/extremist-files/group/alliance-defending-freedom> (last visited Jan. 22, 2018).

224 *Redefining Marriage? EU Court to Rule on National Marriage Laws*, ADF INT’L (Apr. 24, 2017), <https://adfinternational.org/news/redefining-marriage-eu-court-to-rule-on-national-marriage-laws/>.

225 *Alliance Defending Freedom*, *supra* note 223; *ADF and Friends: Hate Group Alliance Defending Freedom Is at the Center of an Anti-LGBTQ Industry*, MEDIA MATTERS FOR AMERICA (Sept. 28, 2017, 9:03 AM), <https://www.mediamatters.org/blog/2017/09/28/adf-and-friends-hate-group-alliance-defending-freedom-center-anti-lgbtq-industry/218066> [hereinafter *ADF and Friends*] (“ADF . . . continued its work supporting the criminalization of gay sex abroad, including Jamaica, Belize, and India”).

226 ILGA, *supra* note 221.



as well as men.<sup>227</sup> Thirteen U.N. member states can impose the death penalty for same-sex sexual contact, although only four implement it.<sup>228</sup> Two of the countries implement the death penalty in provinces, and in two countries it is implemented by non-state actors.<sup>229</sup> In 17 countries, the age of consent to sexual intercourse is different for heterosexual couples and homosexual couples.<sup>230</sup> Nineteen countries have so-called “homosexual propaganda” laws.<sup>231</sup>

Seventy countries, plus Taiwan and Kosovo, prohibit discrimination in the workplace based on sexual orientation, but only 21 protect against discrimination based on gender identity.<sup>232</sup> Merely nine countries include the prohibition of discrimination based on sexual orientation in their constitutions.<sup>233</sup> Forty-three countries protect sexual orientation in their laws concerning hate crimes.<sup>234</sup> Thirty-nine countries prohibit incitement to hatred based on sexual orientation.<sup>235</sup>

There are only 26 countries in the world that allow same-sex couples to marry.<sup>236</sup> In addition, there are 28 countries in which same-sex couples, through civil unions or some other arrangement, can enjoy almost all the rights that marriage affords.<sup>237</sup> However, if one focuses on family, there are merely 26 countries in which it is legal for same-sex couples to adopt together;<sup>238</sup> another 27 allow for second-parent adoptions.<sup>239</sup> This means that there are many LGBT families raising children (who can be LGBT or heterosexual) where it is possible that the law does not recognize the relationship

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227 *Id.*

228 *Id.* at 40.

229 *Id.* Although not a state, there is evidence that Daesh practices the persecution of people because of their sexual orientation or gender identity. *Inside Look at ISIS' Brutal Persecution of Gays*, CBS NEWS (Dec. 2, 2015, 7:17 AM), <http://www.cbsnews.com/news/isis-persecution-gay-men-murder-lgbt-muslim-society/>. This persecution includes imposing the death penalty on people Daesh finds guilty of homosexuality. *Id.*

230 ILGA, *supra* note 221, at 26.

231 *Id.* at 41–42.

232 *Id.*

233 *Id.* at 46–47.

234 *Id.* at 60–63.

235 *Id.* at 63–66.

236 *Gay Marriage Around the World*, PEW RESEARCH CTR (Aug. 8, 2017), <http://www.pewforum.org/2017/08/08/gay-marriage-around-the-world-2013/>.

237 ILGA, *supra* note 221, at 70–72.

238 *Id.* at 73–74.

239 *Id.* at 75–77.



of one of the parents with her/his/their children.

#### F. *Dignity, Religion, and Democracy*

The ADF, previously noted as actively promoting an anti-LGBT agenda abroad, is behind much of the anti-LGBT rights activism in the U.S.<sup>240</sup> ADF's mission statement provides that it works "to keep the doors open for the Gospel by advocating for religious liberty, the sanctity of life, and marriage and family."<sup>241</sup> The goal of the ADF is to establish a rule of law that adopts Christian goals, values and ideologies.<sup>242</sup> ADF promotes and lobbies for passage of the laws that erode or deny LGBT equality protections, and it is at the forefront of initiating, instigating, litigating, and funding litigation to curtail and erode LGBT rights, including marriage rights.<sup>243</sup> It is a driving force behind the push for state religious freedom restoration acts (RFRAs) that have the potential to erode dignity through the democratic process.<sup>244</sup> The ADF not only works with legislation, but it also seeks out litigation to erode LGBT rights. Indeed, the ADF is behind the infamous "gay cake case," *Masterpiece Cakeshop, Ltd. v. Colorado Civil Rights Commission*, which it argued before the Supreme Court on December 5, 2017.<sup>245</sup>

Less than one year after the 2015 *Obergefell* decision, nearly 200 anti-LGBT laws had been proposed in 34 U.S. states.<sup>246</sup> In

240 Posner, *supra* note 222; *ADF and Friends*, *supra* note 225; *Alliance Defending Freedom*, *supra* note 223.

241 FAQ, ALL. DEFENDING FREEDOM, <http://www.adflegal.org/about-us/faq> (last visited Apr. 19, 2018).

242 *Alliance Defending Freedom*, *supra* note 223.

243 *Id.*; Posner, *supra* note 222.

244 *Alliance Defending Freedom*, *supra* note 223.

245 See Michael P. Farris, *Masterpiece Cakeshop Oral Arguments: A View from Inside the Supreme Court*, ALL. DEFENDING FREEDOM (Dec. 8, 2017), <http://www.adflegal.org/details/pages/blog-details/allianceedge/2017/12/08/masterpiece-cakeshop-oral-arguments-a-view-from-inside-the-supreme-court>. The case posed a challenge to an order by the state's civil rights commission that required a bakery owner to stop discriminating against same-sex couples by refusing to sell them wedding cakes. *Masterpiece Cakeshop, Ltd. v. Colo. Civil Rights Comm'n*, 138 S. Ct. 1719, 1723, 1726 (2018). The Supreme Court decided the case on June 4 2018, issuing a narrow holding regarding the commission's procedural actions without reaching the question of whether the order itself was unconstitutional. *Id.* at 1732.

246 Eva Walton Kendrick, *Alabama's Part in Southern Legislative Attacks on LGBT Rights in 2016*, HUMAN RIGHTS CAMPAIGN (Apr. 8, 2016), <https://www.hrc.org/blog/alabamas-part-in-southern-legislative-attacks-on-lgbt-rights->

2015, 17 states approved RFRA-type laws<sup>247</sup> and by 2016, 10 states were considering adopting such laws.<sup>248</sup> In 2017 alone, over 100 anti-LGBT bills have been introduced in 29 states.<sup>249</sup> These laws' exemptions explicitly allow discrimination against the LGBT population based on religious beliefs, even in light of anti-discrimination laws that would otherwise protect LGBT persons, and seek to erode the dignitarian rights LGBT persons have achieved.<sup>250</sup> Those who promote and defend these laws do so on the grounds that these laws are the result of the democratic process at work.<sup>251</sup> These laws clearly unveil the pernicious effect of democracy; they write into law the tyranny of the majority.

For instance, a draconian Mississippi law<sup>252</sup> provides a dramatic example of the discrimination justified by democracy. The law provides that institutions with religious affiliations (including hospitals, schools, emergency services, and more) as well as individuals and private businesses who oppose same-sex marriage (or homosexuality in general) for religious reasons may deny marriage-related services to LGBT people.<sup>253</sup> Services that can be denied include photography, videography, bakery/confectionery, printing of invitations or announcements, car rentals, jewelry sales,

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in-2016.

247 2015 *State Religious Freedom Restoration Legislation*, NAT'L CONFERENCE OF STATE LEGISLATURES, <http://www.ncsl.org/research/civil-and-criminal-justice/2015-state-rfra-legislation.aspx> (last visited Apr. 7, 2017).

248 2016 *State Religious Freedom Restoration Act Legislation*, NAT'L CONFERENCE OF STATE LEGISLATURES, <http://www.ncsl.org/research/civil-and-criminal-justice/2016-state-religious-freedom-restoration-act-legislation.aspx> (last visited Apr. 7, 2017).

249 Susan Miller, *Onslaught of Anti-LGBT Bills in 2017 Has Activists 'Playing Defense,'* USA TODAY (June 1, 2017), <https://www.usatoday.com/story/news/nation/2017/06/01/onslaught-anti-lgbt-bills-2017/102110520/>.

250 See, e.g., *Protecting Freedom of Conscience from Government Discrimination Act*, MISS. CODE ANN. §§ 11-62-1 to 11-62-19 (2017).

251 See e.g., *ADF to Slovak Court: Allow Citizens to Affirm Their Values at Ballot Box*, ADF INT'L (Sept. 30, 2014), <https://adfinternational.org/news/adf-to-slovak-court-allow-citizens-to-affirm-their-values-at-ballot-box/> (“‘The people of Slovakia should have the freedom to preserve marriage and family if they so choose,’ said ADF Senior Legal Counsel Roger Kiska. ‘This referendum will allow Slovaks to affirm current Slovak law and important social values, which is perfectly acceptable under the Slovak Constitution.’”).

252 *Protecting Freedom of Conscience from Government Discrimination Act*, MISS. CODE ANN. §§ 11-62-1 to 11-62-19 (2017).

253 *Id.* § 11-62-5(1), (5).

and wedding venue rentals.<sup>254</sup> The law permits this discrimination under the guise of protecting religious or moral beliefs, including beliefs that marriage may only consist of the union between one man and one woman and that sexual relations are only permissible within such a marriage. This language was almost certainly targeted at LGBT persons. However, notably, by protecting the belief that sexual relations may only occur within a heterosexual marriage, the law also appears to permit discrimination against single parents. Beyond permitting individuals and institutions to deny services based on constitutionally protected conduct, the law permits both employers and school personnel to create discriminatory regulations on dress, appearance, and access to restrooms, other facilities, and services for students and employees based on sex.<sup>255</sup> The law gives “religious organizations” the right to decide, based on their own religious beliefs, whom they employ, dismiss, or discipline.<sup>256</sup> Homeowners can cite their religion as grounds to deny people housing.<sup>257</sup> Religious organizations involved in placing children in private homes for foster care or adoption may refuse to place children in households headed by LGBT people.<sup>258</sup> The law even allows medical personnel to refuse to provide psychological treatment to transgender people or treatment related to sex reassignment or gender identity transitioning.<sup>259</sup> In effect, the law denies the possibility of bringing a case of discrimination based on gender or sexuality against a person or institution in a vast number of settings as long as the reason for discrimination is her/his/their/its religious belief.<sup>260</sup>

Interestingly, civil society’s reaction against these laws has been impressive. Private companies have refused to conduct business in states that discriminate; many have voiced opposition

254 *Id.* § 11-62-5(5).

255 *Id.* § 11-62-5(5), (6).

256 *Id.* § 11-62-5(1)(b). *Religious organizations* are broadly defined to include “[a] religious group, corporation, association, school or educational institution, ministry, order, society or similar entity, regardless of whether it is integrated or affiliated with a church or other house of worship” and owners and agents of such entities. *Id.* § 11-62-17(4).

257 *Id.* § 11-62-5(1)(c).

258 *Id.* § 11-62-5(2).

259 *Id.* § 11-62-5(4).

260 H.R. 1523, 2016 Leg., Reg. Sess. (Miss. 2016), <http://billstatus.ls.state.ms.us/documents/2016/pdf/HB/1500-1599/HB1523SG.pdf> (last visited Apr. 6, 2016).

to the laws.<sup>261</sup> Many are also supporting the repeal of the laws.<sup>262</sup> Furthermore, governors of some states and mayors of seven major cities have prohibited official business travel to states with such laws.<sup>263</sup> One can imagine Hope leading the charge against any and all of these pillars of inequality.

### ***G. Coming Full Circle: Dignity and the Indivisibility and Interdependence Paradigm***

Significantly, by depriving LGBT people of their rights, these new laws strangely elucidate the indivisibility framework that Hope centered in her work. As the Mississippi example shows, these laws deprive LGBT people of not only their civil rights, but also their social and economic rights. These laws affect LGBT people's ability to get employment, their ability to obtain housing, their ability to obtain health care, their access to education, and their right to form a family. As such, these laws deny LGBT people the dignity that all human beings deserve. The fight against such soulless deprivations is precisely what Hope's work represents.

Because democracy cannot, and should not, be supreme over dignity, it is useful to imagine what rights are central to human dignity in the legal framework.<sup>264</sup> Following the healthcare

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261 See, e.g., David A. Graham, *The Business Backlash to North Carolina's LGBT Law*, THE ATLANTIC (Mar. 25, 2016), <https://www.theatlantic.com/politics/archive/2016/03/the-backlash-to-north-carolinas-lgbt-non-discrimination-ban/475500/>; Mary Emily O'Hara, *Tennessee Businesses Form Coalition to Oppose Anti-LGBTQ Laws*, NBC NEWS (Dec. 13, 2016), <https://www.nbcnews.com/feature/nbc-out/tennessee-businesses-form-coalition-oppose-anti-lgbtq-laws-n695606>; Mollie Reilly, *Businesses Are Joining The Fight Against North Carolina's Anti-LGBT Law*, HUFFINGTON POST (Mar. 24, 2016), [https://www.huffingtonpost.com/entry/businesses-nc-anti-lgbt-law\\_us\\_56f42b8ee4b0c3ef52184903](https://www.huffingtonpost.com/entry/businesses-nc-anti-lgbt-law_us_56f42b8ee4b0c3ef52184903).

262 See, e.g., Stephen Peters, *140 Major CEOs & Business Leaders Urging North Carolina to Repeal Discriminatory Anti-LGBT Law*, HUMAN RIGHTS CAMPAIGN (Apr. 1, 2016), <https://www.hrc.org/blog/more-businesses-join-list-of-over-140-ceos-leaders-urging-nc-to-repeal-anti>.

263 Willa Frej, *Several States Ban Official Travel to Mississippi over Anti-Gay Law*, HUFFINGTON POST (Apr. 6, 2016), [https://www.huffingtonpost.com/entry/several-states-ban-official-travel-to-mississippi-over-anti-gay-law\\_us\\_5704f54ce4b0a506064d9a26](https://www.huffingtonpost.com/entry/several-states-ban-official-travel-to-mississippi-over-anti-gay-law_us_5704f54ce4b0a506064d9a26); *States, Cities Ban Employee Travel to Mississippi, N.C.*, USA TODAY (Apr. 6, 2016), <https://www.usatoday.com/story/news/politics/2016/04/06/mississippi-north-carolina-travel-bans/82705866/>.

264 See BLANC, *supra* note 131 (arguing that freedom of the press, freedom of conscience, freedom of association, the right of assembly, and the right to subsist by working shall not depend on a vote of the majority).

model, it is possible to imagine a human rights dignity umbrella. Such a vision would not only underscore the interconnectedness of rights, but also encompass those rights that are necessary for us to thrive as human beings, those rights that ensure our dignity, and those rights that are not subject to the rule of the majority. The contents of a dignity umbrella would include the plethora of topics that Hope promoted: shelter; health; education; family; privacy in association; liberty, peace and security; equality and non-discrimination; adequate living standards; safe environment; nutrition and water; social security. Access to these rights promotes dignity. Democracy does not always work, especially if there are marginable persons who are insular minorities in a society.

A dignity umbrella creates a foundation of inalienable, indivisible, interdependent rights that are critical to human thriving. If a right is on the umbrella—and those rights addressed in this work should be—a resolution of conflict cannot have a dignitarian right cede to a majority interest. Dignitarian rights, as fundamental rights, constitute a matter of justice, not of the ballot box.

## **A Sliver of Hope: Analyzing Voluntary Licenses to Accelerate Affordable Access to Medicines**

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## I. Introduction

This article is written in honor of one of my global human rights heroes, Professor Hope Lewis, who died December 6, 2016. Hope's human rights interests and insights were catholic and keen. However, her own life experience and life struggles with illness and disability gave her special insights into structural determinants of health, the labyrinths of health systems, the social supports needed by those struggling to live, and the centrality of medicines to physical and psychic well-being. Hope was also deeply aware of the excesses of corporate power and the degree to which multinational corporations and rich country governments neglect and abuse human rights, including the right to health, in the Global South. Nonetheless, she maintained a sliver of hope about emerging movements, pressing for social responsibility and human rights accountability by powerful industries and the rich countries that support their interests. I hope this article is a fitting tribute to that sliver of hope, as it describes an emerging practice of voluntary licenses forged in the crucible of activist struggles that has significantly accelerated access to affordable medicines for people living with HIV and hepatitis C in many—but regrettably not all—low- and middle-income countries (LMICs).

As a result of global AIDS activism, governments' latent and exercised powers to bypass pharmaceutical monopolies, and halting pharmaceutical industry accommodation, a new form of voluntary licensing<sup>1</sup> has emerged focused on first permitting and then facilitating generic production of certain pharmaceutical products for sale and use in LMICs. These so-called "access" voluntary licenses (VLs) are pluralistic in detail and not free of commercial motivations for either originators or generic producers, but they do differ from arms-length, purely commercial licenses that have been broadly used in the industry for decades.<sup>2</sup> Although the first

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1 This article will focus on down-stream voluntary licenses (VLs) to exploit or waive intellectual property (IP) rights, including patents, to allow manufacturing and distribution of active pharmaceutical ingredients (APIs) and final formulations by generic producers for sale in low- and middle-income countries (LMICs). This discussion will exclude mere marketing/distribution arrangements and contract production of authorized originator generics. Similarly, this discussion will also exclude discussions of up-stream VLs focused on increasing access to patented technologies, compounds, and biologics for the purpose of product research and development.

2 See generally Daniel Simonet, *Licensing Agreements in the Pharmaceutical Industry*, 2 INT'L J. MED. MARKETING 329 (2002), <https://www.researchgate.net/>

of these access VLs were negotiated bilaterally by innovators at the receiving end of AIDS activism and threats of government action, including the issuance of compulsory or government-use licenses,<sup>3</sup> the leading model of more public-health oriented VLs can be traced to the formation of the Medicines Patent Pool (MPP) under the financial sponsorship of Unitaid in 2010.<sup>4</sup> The history of the MPP has been chronicled briefly,<sup>5</sup> but the details of MPP and other access VLs have not been closely scrutinized in legal scholarship and certainly not from a human rights, access-to-medicines perspective.

The primary goals of this article are: (a) to increase understanding of the history and evolution of access VLs and their key terms and conditions, including their impacts on access to medicines in territories included in and excluded from the licenses; (b) to identify and assess best-practice licensing terms for delivering meaningful access to medicines, including the impact of voluntary licensing practices on registration and uptake; and (c) to make policy recommendations on measures that can be taken to improve terms

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publication/244885066\_Licensing\_Agreements\_in\_the\_Pharmaceutical\_Industry (discussing commercially-oriented VLs).

- 3 Unlike VLs, compulsory and government-use licenses are issued by a government to allow a competitor to exploit a patent based on statutory grounds and specified procedures, and upon payment of adequate compensation to the right holder. Compulsory licenses can allow for domestic production, sale, and use, but can also be granted to foreign licensees who would import the product into the issuing country market. See BROOK K. BAKER, DEP'T FOR INT'L DEV. HEALTH SYS. RES. CTR., PROCESSES AND ISSUES FOR IMPROVING ACCESS TO MEDICINES 7, 14 (2004), [http://www.iprsonline.org/resources/docs/Baker\\_TRIPS\\_Flex.pdf](http://www.iprsonline.org/resources/docs/Baker_TRIPS_Flex.pdf); Brook K. Baker, *Arthritic Flexibilities for Accessing Medicines: Analysis of WTO Action Regarding Paragraph 6 of the Doha Declaration on the TRIPS Agreement and Public Health*, 14 IND. INT'L & COMP. L. REV. 613, 615–18, 662–63 (2004).
- 4 Resolution No. 7: Memorandum of Understanding between UNITAID and Medicines Patent Pool Foundation, UNITAID (June 8–9, 2010), [https://unitaid.eu/assets/07\\_eb12-res7-mou-patent-pool.pdf](https://unitaid.eu/assets/07_eb12-res7-mou-patent-pool.pdf); Memorandum of Understanding between the World Health Organization and the Medicines Patent Pool Foundation, WORLD HEALTH ORG. [WHO] (Sept. 14, 2010) (on file with author) [hereinafter *MPP-WHO Memorandum of Understanding*].
- 5 See generally Jorge Bermudez & Ellen 't Hoen, *The UNITAID Patent Pool Initiative: Bringing Patents Together for the Common Good*, 4 OPEN AIDS J. 37 (2010), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2842943/pdf/TOAIDJ-4-37.pdf>; Michelle Childs, *Towards a Patent Pool for HIV Medicines*, 4 OPEN AIDS J. 33 (2010), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2817875/pdf/TOAIDJ-4-33.pdf>; Krista L. Cox, *The Medicines Patent Pool: Promoting Access and Innovation for Life-Saving Medicines through Voluntary Licenses*, 4 HASTINGS SCI. & TECH. L.J. 291 (2012).

and conditions of access VLs, including those of the MPP. Although the complementarity of voluntary licensing strategies with other access strategies, including law reform, use of opposition procedures, and grant of compulsory and government-use licenses is important, these topics will only be addressed briefly in the conclusion.

## **II. A Public Health/Human Rights Framework of Access to Medicines and the Intellectual Property/Regulatory Context of this Analysis**

This article adopts a human rights framework focused on achieving the widest possible access to affordable medicines of assured quality. A human rights approach to access to medicines is founded on the right to health, which guarantees that people who need access to an essential medicine can have such access on a non-discriminatory, equitable, and affordable basis no matter where they live or what their status.<sup>6</sup> Historically, rich people in rich countries have had an “express lane” to the medicines that they need—research and development is focused on their health priorities and newly discovered medicines are rushed to their markets. In contrast, poorer people, especially those in LMICs, have had limited or no access to medicines focused on their priority needs to the newest medicines, to medicines well adapted to their circumstances, or to medicines that are affordable.<sup>7</sup> Access to well-adapted, affordable medicines of assured quality for LMICs is plagued by market failures in research

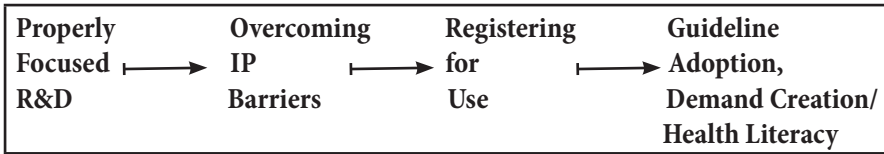
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6 Yousuf A. Vawda & Brook K. Baker, *Achieving Social Justice in the Human Rights/Intellectual Property Debate: Realising the Goal of Access to Medicines*, 13 AFR. HUM. RTS. L.J. 55, 57–81 (2013); Brook K. Baker, *Placing Access to Essential Medicines on the Human Rights Agenda*, in *THE POWER OF PILLS: SOCIAL, ETHICAL & LEGAL ISSUES IN DRUG DEVELOPMENT, MARKETING & PRICING* 239, 239–248 (Jillian Clare Cohen et al. eds., 2006).

7 See generally Comm’n on Intellectual Prop. Rights, Innovation and Pub. Health, *Public Health, Innovation and Intellectual Property Rights*, WHO 15–17 (2006), <http://www.who.int/intellectualproperty/documents/thereport/ENPublicHealthReport.pdf?ua=1> (describing the differing market incentives for medicines addressing priority health needs in rich countries and poor countries).

priorities,<sup>8</sup> intellectual property (IP) exclusivities,<sup>9</sup> regulatory barriers,<sup>10</sup> lack of treatment guidelines,<sup>11</sup> and weak demand creation and treatment literacy for patients and communities.<sup>12</sup> Guaranteeing affordable access to needed medicines requires overcoming all of these barriers for the broadest number of patients in the quickest time possible.

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- 8 Patrice Trouiller et al., *Drug Development for Neglected Diseases: A Deficient Market and a Public-Health Policy Failure*, 359 *LANCET* 2188 (2002); Peter J. Hotez, *The Poverty-Related Neglected Diseases: Why Basic Research Matters*, *PLOS BIOLOGY*, (Nov. 9, 2017), <http://journals.plos.org/plosbiology/article?id=10.1371/journal.pbio.2004186>; Jürg Utzinger & Jennifer Keiser, *Comment: Research and Development for Neglected Diseases: More is Still Needed, and Faster*, 1 *LANCET GLOBAL HEALTH* e317 (2013), [http://www.thelancet.com/pdfs/journals/langlo/PIIS2214-109X\(13\)70148-7.pdf](http://www.thelancet.com/pdfs/journals/langlo/PIIS2214-109X(13)70148-7.pdf) (citing continuing insufficiency in the pipeline of new medicines for neglected diseases).
- 9 The primary IP exclusivities at issue are patents, data and registration-related exclusivity, and trade secrets.
- 10 The primary regulatory barriers are: (1) registering originator medicines and their generic equivalents for sales in LMICs; (2) meeting global standards of Good Manufacturing Practice and pre-approval by stringent regulatory authorities and/or the WHO Prequalification Program; (3) meeting other funder and licensor requirements; and (4) receiving permissions to export, distribute, warehouse, and import medicines as needed.
- 11 The WHO regularly develops and updates evidence-based treatment guidelines for prevalent diseases, listing preferred treatment regimens. *Guidelines Review Committee*, *WORLD HEALTH ORG.*, [http://www.who.int/publications/guidelines/guidelines\\_review\\_committee/en/](http://www.who.int/publications/guidelines/guidelines_review_committee/en/) (last visited June 12, 2018) (describing how guidelines are developed); *See Documents Listed Alphabetically*, *WORLD HEALTH ORG.*, <http://www.who.int/publications/guidelines/atoz/en/> (last visited June 12, 2018) (listing all current guidelines, including treatment guidelines). This normative guidance is then frequently taken up by national governments, but often with delays. The absence of a medicine, including one for which a VL has been granted, can result in an absence of effective demand for the product in treatment tenders, thereby also delaying generic entry.
- 12 Addressing the need for treatment literacy, community engagement, and community-based service delivery is seen as essential in the AIDS response. *See UNAIDS & MÉDECINS SANS FRONTIÈRES [MSF] BELG., ENGAGING THE COMMUNITY TO REACH 90-90-90: A REVIEW OF EVIDENCE AND IMPLEMENTATION STRATEGIES IN MALAWI* (2015), [https://www.msf.org/sites/msf.org/files/engaging\\_the\\_community\\_to\\_reach\\_90-90-90.pdf](https://www.msf.org/sites/msf.org/files/engaging_the_community_to_reach_90-90-90.pdf); *UNAIDS, TREATMENT 2015*, at 23–26 (2012), [http://www.unaids.org/sites/default/files/media\\_asset/JC2484\\_treatment-2015\\_en\\_1.pdf](http://www.unaids.org/sites/default/files/media_asset/JC2484_treatment-2015_en_1.pdf) (describing Pillar 1 of the AIDS response: demand). *See Treatment Education & Research*, *INT’L TREATMENT PREPAREDNESS COAL.*, <http://itpcglobal.org/our-work/treatment-education-knowledge/> (last visited June 12, 2018) (summarizing ITPC’s treatment literacy activities).



Substantial evidence suggests that access to affordable medicines in most contexts is best achieved by promoting robust generic competition in aggregated markets that incentivizes generic entry, production at economies-of-scale, and competition over efficient production methods and prices. Médecins Sans Frontières (MSF), in *Untangling the Web of Antiretroviral Prices*,<sup>13</sup> has long proven this point, showing over and over again that as more generics enter the market and as volumes grow, antiretroviral (ARV) prices typically go down,<sup>14</sup> ordinarily to a tiny fraction of the best access price offered by patent right holders even in low-income countries. Of course, at some point final economies-of-scale are reached and costs become inelastic, in which case it is important that sufficient earnings margins be maintained so that market viability is assured.<sup>15</sup>

13 See *Untangling the Web of Antiretroviral Prices*, MSF, <https://www.msfacecess.org/content/untangling-web-antiretroviral-price-reductions> (last visited June 12, 2018) (containing 14 years of reports on this issue).

14 There are occasional exceptions when second- and third-line generic antiretrovirals (ARVs) first enter the market, particularly at low volumes, where originators adopt a low-price policy to deter generic competition, as Abbott Laboratories/AbbVie did with ritonavir/lopinavir, or where production processes are particularly complex and hard to duplicate because of their trade secret status. See *Abbott's Commitment to Global HIV Care*, BUSINESS & HUMAN RIGHTS RESOURCE CENTRE, <https://www.business-humanrights.org/sites/default/files/media/bhr/files/Abbott-commitment-to-global-HIV-care-May-2007.pdf> (discussing Abbott's early pricing practice that at least initially undercut generic prices).

15 For the importance of sustaining viable markets, see Brenda Waning et al., *Intervening in Global Markets to Improve Access to HIV/AIDS Treatment: An Analysis of International Policies and the Dynamics of Global Antiretroviral Medicines Markets*, 6 GLOBALIZATION & HEALTH, at 16–17 (2010), <https://globalizationandhealth.biomedcentral.com/articles/10.1186/1744-8603-6-9>. More broadly this article found:

Global initiatives facilitated the creation of fairly efficient markets for older ARVs, but markets for newer ARVs are less competitive and slower to evolve. WHO guidelines shape demand, and their complexity may help or hinder achievement of economies-of-scale in pharmaceutical manufacturing. Certification programs assure ARV quality but can delay uptake of new formulations. Large-scale procurement policies may decrease the numbers of buyers and sellers, rendering the market less competitive in the



Voluntary licensing and other access strategies dealing with IP barriers, including but not limited to law reform, patent oppositions, and compulsory and government-use licenses, must be analyzed in an overarching global context where multinational pharmaceutical companies have attained a high degree of hegemonic, monopolistic control on the manufacturing, distribution, and pricing of pharmaceutical products via intensive utilization of IP as a tool to retain and prolong market monopolies. This hegemony is facilitated by the global expansion of patenting on pharmaceuticals and other medical tools pursuant to the World Trade Organization (WTO) Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS),<sup>16</sup> other IP protection rules set forth in free trade agreements (FTAs) and investment treaties, and conforming national patent laws.

Reliance on VLS as one tool to expand access to pharmaceuticals and other medical products arises from the need to bypass exclusive rights in the form of patents, data/registration-related protections, and trade secrets. Patent rights and data protection rights were harmonized to global minimum standards pursuant to the TRIPS Agreement in 1995, which was in turn subject to certain transitional periods.<sup>17</sup> Trade secret rights are not yet globally harmonized and are instead typically determined by national legislation or common law.<sup>18</sup> However, there are growing efforts to create globally or regionally

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long-term. Global policies must be developed with consideration for their short- and long-term impact on market dynamics.

*Id.* at 1.

- 16 Agreement on Trade-Related Aspects of Intellectual Property Rights, art. 8(1), Apr. 15, 1994, Marrakesh Agreement Establishing the World Trade Organization, Annex 1C, 33 I.L.M. 81 [hereinafter TRIPS Agreement].
- 17 General transition periods are contained in Articles 65 and 66. Least Developed Country (LDC) Members currently have a 2021 extension with respect to general TRIPS compliance. Council for Trade-Related Aspects of Intellectual Property Rights, *Extension of the Transition Period Under Article 66.1 for Least Developed Country Members*, WTO Doc. IP/C/64 (June 11, 2013). A transition period with respect to pharmaceutical products has been extended until 2033. See Press Release, World Trade Org., WTO Members Agree to Extend Drug Patent Exemption for Poorest Members (Nov. 6, 2015), [https://www.wto.org/english/news\\_e/news15\\_e/trip\\_06nov15\\_e.htm](https://www.wto.org/english/news_e/news15_e/trip_06nov15_e.htm); *TRIPS Report on Least Developed Country Members*, WTO Doc. IP/C/73 (Nov. 8, 2015) [hereinafter *TRIPS Report on Least Developed Country Members*].
- 18 See Ass'n Internationale pour la Protection de la Propriété Intellectuelle [AIPPI], *Summary Report Question Q215: Protection of Trade Secrets through IPR and Unfair Competition Law* (2010), <https://aippi.org/wp-content/uploads/committees/215/SR215English.pdf>.



harmonized trade secret law<sup>19</sup> and to pressure countries, crucially including India, to modify its existing trade secret regime.<sup>20</sup>

Except with respect to WTO members who are classified as Least Developed Countries (LDCs) or countries that are not members of the WTO, pharmaceutical right holders can now file pharmaceutical patent applications in virtually every country pursuant to the World Intellectual Property Organization (WIPO) Patent Cooperation Treaty.<sup>21</sup> Many pharmaceutical right holders are increasingly doing so,<sup>22</sup> especially in countries with significant potential markets and countries with pharmaceutical manufacturing capacity. Meanwhile, national patent laws remain significantly diversified with substantive provisions and procedures differing country-to-country, revealing policy space for flexibilities allowed under the TRIPS Agreement.<sup>23</sup>

Aggregating multinational markets is difficult because of the territoriality of exclusive IP rights, particularly patent rights. Patent rights are granted country-by-country, meaning that there is no such thing as a global patent.<sup>24</sup> However, the patent

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- 19 See Jennifer Brant & Sebastian Lohse, *Trade Secrets: Tools for Innovation and Collaboration* (Int'l Chamber of Commerce, 2014), <https://cdn.iccwbo.org/content/uploads/sites/3/2017/02/ICC-Research-Trade-Secrets-english.pdf>; see, e.g., CORP. EUR. OBSERVATORY, *TOWARDS LEGALISED CORPORATE SECRECY IN THE EU?* (2015), [https://corporateurope.org/sites/default/files/attachments/trade\\_secrets\\_protection\\_lobbying\\_report\\_-\\_final.pdf](https://corporateurope.org/sites/default/files/attachments/trade_secrets_protection_lobbying_report_-_final.pdf).
- 20 Pratik Das, *India's Protection to Secrets of Trade*, KHURANA & KHURANA (Aug. 26, 2017, 7:40 AM), <http://www.khuranaandkhurana.com/2017/08/26/indias-protection-to-secrets-of-trade/>; Press Release, Office of the U.S. Trade Rep. (USTR), *India and United States Joint Statement on the Trade Policy Forum* (Oct. 20, 2016).
- 21 Patent Cooperation Treaty, June 19, 1970, 28.7 U.S.T. 7645, 1160 U.N.T.S. 18336, [http://www.wipo.int/wipolex/en/treaties/text.jsp?file\\_id=288637](http://www.wipo.int/wipolex/en/treaties/text.jsp?file_id=288637) (as modified on Oct. 3, 2001).
- 22 RWS INOVIA, *THE 2017 GLOBAL PATENT & IP TRENDS INDICATOR* (2017), <http://patentdocs.typepad.com/files/the-2017-u.s.-global-patent-ip-trends-indicator.pdf>; Steve Brachmann, *Global IP Trends Indicator Underscores Increasing Globalization in Patent Filing Strategies*, IPWATCHDOG (July 28, 2017), <http://www.ipwatchdog.com/2017/07/28/global-ip-trends-underscoresincreasing-globalization-patent-filingstrategies/id=86099/>.
- 23 See John F. Duffy, *Harmony and Diversity in Global Patent Law*, 17 BERKELEY TECH. L.J. 685, 705, 719 (2002).
- 24 Note there are some regional processes that grant patents for their participants including the African Regional Intellectual Property Organization (ARIPO). See, e.g., *About ARIPO*, ARIPO, <http://www.aripo.org/about-aripo> (last visited July 1, 2018); *Spécificités du Système*, ORGANISATION AFRAICAINE DE LA PROPRIÉTÉ INTELLECTUELLE, <http://www.oapi.int/index.php/en/aipo/>

landscape of a medicine can block access in a particular country based on: (1) the patent status of the active pharmaceutical ingredient (API) and other key prodrugs and intermediaries in their country of production, (2) the patent status of final formulation medicine in the country of production/export, and (3) the patent status of the medicine in the country of sale and use, including via importation. It is key to understand that if the right holder has patent protections in the country of production on the API or of final formulation manufacture, the right holder can essentially block supply to a country requiring importation even if there is no patent in effect absent the use of flexibilities like compulsory licenses or parallel importation discussed further below. It is also important to understand that right holders often have multiple patents on a single medicine, including Markush claims; derivatives; formulation/dosage patents; patents on intermediates; new use/indication and method-of-use patents; and new manufacturing processes.<sup>25</sup> In some countries, an extension of patent terms on pharmaceuticals could also be resorted to by the right holder to compensate for time awaiting patent examination and/or the time waiting for regulatory approval by the national medicines regulatory authority. Patent term extensions,<sup>26</sup> patent term restoration, and supplementary protection certificates<sup>27</sup> are

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specificites-du-systeme; *EAPO: A History of Establishment and Development*, EURASIAN PATENT ORGANIZATION (2015), <https://www.eapo.org/en/publications/reports/report2015/history.html> (detailing the history of the Eurasian patent landscape and the development of the Eurasian Patent Organization).

25 For example, there are over 800 families of patents on the key booster ARV, ritonavir. See LANDON IP, PATENT LANDSCAPE REPORT ON RITONAVIR (2011), [http://www.wipo.int/edocs/pubdocs/en/patents/946/wipo\\_pub\\_946.pdf](http://www.wipo.int/edocs/pubdocs/en/patents/946/wipo_pub_946.pdf). For a discussion of different kinds of product-related patents, see CARLOS CORREA, GUIDELINES FOR THE EXAMINATION OF PATENT APPLICATIONS RELATING TO PHARMACEUTICALS 21–24, 27, 36–37, 42 (2016), <http://www.undp.org/content/undp/en/home/librarypage/hiv-aids/guidelines-for-the-examination-of-patent-applications-relating-t.html>.

26 See, e.g., 35 U.S.C. § 154; 37 C.F.R. § 1.702–705; U.S. PATENT & TRADEMARK OFFICE, MANUAL OF PATENT EXAMINING PROCEDURE (9th ed. 2018), <https://www.uspto.gov/web/offices/pac/mpep/s2750.html>.

27 See, e.g., *Supplementary Protection Certificates for Pharmaceutical and Plant Protection Products*, EUROPEAN COMMISSION, [https://ec.europa.eu/growth/industry/intellectual-property/patents/supplementary-protection-certificates\\_en](https://ec.europa.eu/growth/industry/intellectual-property/patents/supplementary-protection-certificates_en) (last updated June 17, 2018) (defining a supplementary protection certificate as an extension of the original 20-year patent term to compensate for the time period between the filing of the patent and the authorization to market the

not obligatory under TRIPS, but can effectively delay the generic competition where they are available.

Other exclusive rights, besides patent rights, can also block production and sale of generic medicines. For example, because of inadequate disclosure in patent applications, it might be very difficult for a generic manufacturer to actually make a generic copy of a more complicated medicine. Many drug companies “hide” some of their technical information about the best way to manufacture a medicine in the form of trade-secret-protected “know-how.”<sup>28</sup> In addition, in some jurisdictions, originator companies are granted exclusive rights over registration-related clinical data—data exclusivity—and thus can block drug regulatory authorities from relying upon or referencing that data when they are processing marketing approval for a generic equivalent.<sup>29</sup> Data exclusivity could block generic entry even when there is no patent in force in the country. In addition to these data-exclusivity monopolies, some countries also grant patent-registration linkage rights to patent holders to block registration of a generic product whenever the patent holder asserts that a granted patent would be infringed by the generic equivalent.<sup>30</sup>



Another legal issue affecting access to medicines is registration or marketing approval based on the proven safety, efficacy, and quality of the medicines.<sup>31</sup> As a practical matter, medicines are ordinarily legally available only if they have been registered (granted marketing approval) by a country’s medicines regulatory authority, although some countries allow importation from countries where the product has been registered by stringent

patented medicine with an upper overall maximum of 15 year to exclusivity).

28 Note: hiding technical information is not an issue for most Indian generics at least with respect to small molecule medicines.

29 Brook K. Baker, *Ending Drug Registration Apartheid – Taming Data Exclusivity and Patent/Registration Linkage*, 34 AM. J.L. & MED. 303, 306, 33, 324 n.24 (2008).

30 *Id.* at 307.

31 See WHO, *WHO Expert Committee on Specifications for Pharmaceutical Products*, annex 9 (2015), [http://www.who.int/medicines/areas/quality\\_safety/quality\\_assurance/Annex9-TRS992.pdf?ua=1](http://www.who.int/medicines/areas/quality_safety/quality_assurance/Annex9-TRS992.pdf?ua=1).

regulatory authorities and where manufacturing facilities have been inspected for Good Manufacturing Practices.<sup>32</sup> However, in addition to national registration, most global health initiatives,<sup>33</sup> especially in the HIV context, require World Health Organization (WHO) Prequalification,<sup>34</sup> prior registration by a stringent regulatory authority,<sup>35</sup> or review by an Expert Review Panel.<sup>36</sup> In whichever form, getting regulatory approval is indispensable to ensure sustainable supply of medicines in a country of concern. Without such measures, any promise of access is empty. Registration is a persistent problem since both originator and generic companies often delay or exclude registration in certain LMICs because of various factors such as registration barriers, small market size, and disproportionate cost/benefit ratios.<sup>37</sup> Generics may be further deterred from registering their generic equivalents if the medicine has not yet been adopted

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32 See *Guidelines on Import Procedures for Pharmaceutical Products*, WHO TECHNICAL SUPPORT SERIES NO. 863 (1996), [http://www.who.int/medicines/areas/quality\\_safety/quality\\_assurance/GuidelinesImportProceduresPharmaceuticalProductsTRS863Annex12.pdf?ua=1](http://www.who.int/medicines/areas/quality_safety/quality_assurance/GuidelinesImportProceduresPharmaceuticalProductsTRS863Annex12.pdf?ua=1).

33 See, e.g., *Global Fund Quality Assurance Policy for Pharmaceutical Products*, THE GLOBAL FUND, [https://www.theglobalfund.org/media/5894/psm\\_qapharm\\_policy\\_en.pdf?u=636613753480000000](https://www.theglobalfund.org/media/5894/psm_qapharm_policy_en.pdf?u=636613753480000000) (last updated Dec. 14, 2010).

34 *Compare Essential Medicines and Health Products: Prequalification of Medicines*, WORLD HEALTH ORG., <http://apps.who.int/prequal/>, with U.S. DEPT OF STATE ET AL., U.S. PRESIDENT'S EMERGENCY PLAN FOR AIDS RELIEF, <http://www.pepfar.gov/documents/organization/107821.pdf> (requiring U.S. Food and Drug Administration approval or tentative approval).

35 National drug regulatory authorities that are members or observers or associates of the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use are considered Stringent Regulatory Authorities for the Global Fund. See *List of Countries Considered as Stringent Regulatory Authorities (SRA) from 1st July 2009*, STOP TB PARTNERSHIP, [http://www.stoptb.org/assets/documents/gdf/drugsupply/List\\_of\\_Countries\\_SRA.pdf](http://www.stoptb.org/assets/documents/gdf/drugsupply/List_of_Countries_SRA.pdf) (last visited June 14, 2018). For details on ICH, see generally INT'L COUNCIL FOR HARMONISATION OF TECH. REQUIREMENTS FOR PHARMACEUTICALS FOR HUMAN USE, ICH HARMONIZATION FOR BETTER HEALTH, <http://www.ich.org/home.html> (last visited June 14, 2018).

36 See World Health Org. Prequalification of Meds. Programme, Briefing Paper: Expert Review Panel (Apr. 27, 2012), <http://apps.who.int/medicinedocs/documents/s19247en/s19247en.pdf>.

37 Brook K. Baker, *Drug Registration Barriers and Logjams*, in MISSING THE TARGET #5: IMPROVING AIDS DRUG ACCESS AND ADVANCING HEALTH CARE FOR ALL 49-58 (2007).

in WHO and national treatment guidelines,<sup>38</sup> if the originator has not filed for registration in a particular country meaning the generic registrant might need to meet higher registration standards for a new drug application,<sup>39</sup> and if they have not received required import/export permissions.<sup>40</sup> Collecting information about the registration status of a medicine in multiple countries is extremely difficult. Many countries do not have accessible, updated, or comprehensive databases on registration. There is also no global informational resource. Individual pharmaceutical companies rarely publish such information in a systematic manner except in some occasions under so called “access programs.” Finally, licensors and licensees to the MPP currently consider country specific registration data to be confidential. As will be discussed later, lacking reliable and verifiable public information on registration status makes it difficult to measure the actual impact of VLs.



This article attempts to assess voluntary licensing as one part of a broader matrix of access-to-medicines strategies. The article expressly acknowledges that voluntary licensing as an access strategy is currently restricted to a limited number of diseases, most especially HIV and more recently hepatitis C. The use of voluntary licensing for other medicines, whether in a bilateral context or through the MPP, is highly uncertain, though one company, GlaxoSmithKline, has recently expressed an intention to license cancer medicines for some LMICs via the MPP.<sup>41</sup>

38 In some instances, there is a vicious circle because WHO might not recommend a medicine if it is not yet widely available and ready to market.

39 U. Nitin Kashyap et al., *Comparison of Drug Approval Process in United States & Europe*, 5 J. PHARMACEUTICAL SCI. & RES. 131 (2013), <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.375.519&rep=rep1&type=pdf>.

40 See, e.g., U.S. DEP'T OF HEALTH & HUMAN SERVS. FOOD & DRUG ADMIN., GUIDANCE FOR INDUSTRY: EXPORTS UNDER THE FDA EXPORT REFORM AND ENHANCEMENT ACT OF 1996 (2007), <https://www.fda.gov/downloads/RegulatoryInformation/Guidances/ucm125898.pdf>.

41 See Press Release, GlaxoSmithKline, GSK Expands Graduated Approach to Patents and Intellectual Property to Widen Access to Medicines in the World's Poorest Countries (Mar. 31, 2016), <https://www.gsk.com/en-gb/media/press-releases/gsk-expands-graduated-approach-to-patents-and-intellectual>

The ultimate impact of voluntary licensing on the ground in terms of affordable access to medicines is highly country specific, closely linked to whether a given country is included within the direct and indirect territory coverage of a license, the patent and regulatory status of the products, as well as the extent to which a country has effective health systems and policies. Current access licenses routinely exclude certain middle-income countries (MICs), always China and Brazil and usually other so-called pharmerging countries.<sup>42</sup> Since VLs are voluntary mechanisms, and given the commercial motivations and interests of pharmaceutical innovators and IP right holders to access economic elites and growing middle-class patients in larger and relatively richer countries, it is appropriate to pay close attention to the market intentions of drug companies and their practices and perspectives with respect to territorial inclusion. It is also important to assess how such companies may be using VLs and other “market-capture strategies” to foreclose flexibility for governments in such markets to increase access. Huge uncertainty remains with the actual impact of voluntary access licenses for countries that are excluded from coverage and yet could be eligible for generic supply if no patent was in force. Despite the importance of concern about access in excluded MICs, it is important to focus as well on the positive health impacts of access licenses in terms of affordable prices and increased access to life-saving and life-enhancing medicines.

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property-to-widen-access-to-medicines-in-the-world-s-poorest-countries/.

42 Twenty-two countries are now considered “pharmerging” based on market size and prospects in Quintiles IMS Institute for Healthcare Informatics. QUINTILESIMS INST., OUTLOOK FOR GLOBAL MEDICINES THROUGH 2021: BALANCING COST AND VALUE 44–49 (2016), [https://www.iqvia.com/-/media/iqvia/pdfs/institute-reports/global-outlook-for-medicines-through-2021.pdf?la=en&hash=6EA26BACA0F1D81EA93A74C50FF60214044C1DAB&\\_=1517325781735](https://www.iqvia.com/-/media/iqvia/pdfs/institute-reports/global-outlook-for-medicines-through-2021.pdf?la=en&hash=6EA26BACA0F1D81EA93A74C50FF60214044C1DAB&_=1517325781735). China is in the Tier One class as it has enormous market potential because of its population size, growing wealth, and increased use of Western medicines. Brazil, Russia, and India are Tier Two countries, while Turkey, Mexico, Poland, Saudi Arabia, Argentina, Indonesia, Egypt, Pakistan, Vietnam, Columbia, Philippines, Algeria, South Africa, Bangladesh, Romania, Chile, Nigeria, and Kazkhstan are classified as Tier Three countries. Since 2011, global expansion in the volume of medicine usage has been driven by pharmerging markets. However, per capita medicine spending varies greatly. Future spending growth is projected lower because of a weakened economic environment and the use of lower priced non-originator products. Nonetheless, pharmaceutical market growth rates in pharmerging countries are projected significantly higher than in developed economies: 6–9% vs. 4–7%, respectively. *Id.* at 9.



### III. A Brief History on the Evolution of VLs Toward Increased Access

Beginning in the early 2000s, primarily because of pressure from AIDS activists compounded by government threats to issue compulsory licenses and to exercise LDC waivers, some pharmaceutical companies began to offer discount prices and/or territorially limited, quasi-commercial VLs or non-assertion/non-enforcement arrangements for HIV ARV medicines, especially in sub-Saharan Africa and in low-income countries.<sup>43</sup> These early, quasi-commercial VLs and non-assertion arrangements were sometimes described as “humanitarian licenses.”<sup>44</sup> However, early, quasi-commercial VL and non-assertion/non-enforcement arrangements should be distinguished from each other. The typical quasi-commercial VLs was a fully developed agreement allowing the licensee(s) to use or share the relevant IP rights in defined territories, for a defined period of time, under highly specified terms and conditions, often in exchange for a royalty payment. These licenses were offered only to a relatively small number of favored generic manufacturers to promote limited competition and greater

43 Boehringer Ingelheim was one of the first innovator companies to announce a non-assert policy on nevirapine, which has since been expanded to cover a total of 135 LMICs, and which has been taken up by 12 WHO prequalified generic manufacturers. See Press Release, Boehringer Ingelheim, Boehringer Ingelheim Increases Access to the Medication for the Treatment of HIV/AIDS (May 25, 2016), <https://www.boehringer-ingelheim.com/press-release/boehringer-ingelheim-increases-access-medication-treatment-hiv-aids>. GlaxoSmithKline was also an early voluntary licensor to Aspen Pharmacare; the license had a royalty rate of 30% and only allowed sales to NGOs and the public sector. Tahir Amin, *Voluntary Licensing Practices in the Pharmaceutical Sector: An Acceptable Solution to Improving Access to Affordable Medicines?*, OXFAM 7 (Feb. 28, 2007), <http://static1.1.sqspcdn.com/static/f/129694/1099999/1192729231567/Oxfam+-+Voluntary+Licensing+Research+IMAK+Website.pdf?token=pr6ebzNwrH3Z8KmdWeYk7MiX7Fc%3D>.

44 Patrick Gaulé & Annamaria Conti, *Universities and Access to Medicines: What is the Optimal ‘Humanitarian License?’*, CHAIR ECON. MGMT. INNOVATION WORKING PAPER 2008-005 (2008), [https://www.researchgate.net/publication/4824537\\_Universities\\_and\\_access\\_to\\_medicines\\_What\\_is\\_the\\_optimal\\_%27humanitarian\\_license%27](https://www.researchgate.net/publication/4824537_Universities_and_access_to_medicines_What_is_the_optimal_%27humanitarian_license%27) (comparing equitable access licenses and humanitarian licenses, especially in the university technology transfer context). For a partial list of early licenses, see Int’l Fed’n Pharmaceutical Mfrs. & Ass’ns [IFPMA], *Policy Position, Voluntary Licenses and Non-Assert Declarations* (Feb. 18, 2015), <https://www.ifpma.org/wp-content/uploads/2016/03/IFPMA-Position-on-VL-and-Non-Assert-Declarations-18FEB2015.pdf>.



access to more affordable medicines; precise terms were usually confidential.<sup>45</sup> Non-assertion/non-enforcement arrangements,<sup>46</sup> in contrast, are not fully negotiated licenses, even though they too define territories and other conditions. Unlike VLs, non-assert agreements do not ordinarily allow parallel import into countries with typical international exhaustion rules because they do not directly offer permission to exercise the exclusive rights.<sup>47</sup> They also

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45 Early VLs are detailed and critiqued in Amin, *supra* note 43, at 7–10. See also Peter Beyer, *Developing Socially Responsible Intellectual Property Licensing Policies: Non-Exclusive Licensing Initiatives in the Pharmaceutical Sector*, in INTELLECTUAL PROPERTY IN THE PHARMACEUTICAL SECTOR 227–256 (Jacques de Werra ed., 2013); REBECCA GOULDING & AMRITA PALRIWALA, RESULTS FOR DEV. INST., PATENT POOLS ASSESSING THEIR VALUE-ADDED FOR GLOBAL HEALTH INNOVATION AND ACCESS 17–19 (2012), [https://www.r4d.org/wp-content/uploads/R4D\\_PatentPoolsReport\\_0215.pdf](https://www.r4d.org/wp-content/uploads/R4D_PatentPoolsReport_0215.pdf); Michael A Friedman et al., *Out-licensing: A Practical Approach for Improvement of Access to Medicines in Poor Countries*, 361 LANCET 341 (2003); Kevin Outterson & Aaron S. Kesselheim, *Market-Based Licensing for HPV Vaccines in Developing Countries*, 27:1 HEALTH AFFAIRS 130, 130–139 (2008), <https://www.healthaffairs.org/doi/pdf/10.1377/hlthaff.27.1.130>.

46 GOULDING & PALRIWALA, *supra* note 45, at 17. These kinds of arrangements are more fully described by Peter Beyer:

Other ways for a rights holder to allow third parties to use a patented invention are through non-assert declarations or non-assertion covenants and immunity-from-suit agreements. In these arrangements the rights holder states that she/he will not assert his/her rights, i.e. not enforce his patent(s). These agreements guarantee that the rights owner will not sue the other party for infringement or alleged infringement of the rights specified in the agreement. Non-assert declarations and immunity-from-suit agreements contain an explicit set of conditions, including permitted actions and designated territories, for which the patent owner commits not to enforce his patent rights. They can take the form of agreements between two or more parties, but can also be issued as unilateral declarations describing the intention of the rights holder not to enforce his rights. The agreements or declarations can have additional conditions; for example, Boehringer-Ingelheim requires that licensed producers be prequalified by WHO to ensure good quality. To avoid legal conflicts it is essential that the scope of the agreements – regarding rights that will not be enforced, activities that will not be considered infringement, as well as territorial and other possible conditions for non-enforcement – are clearly set out in the agreements or declarations.

Beyer, *supra* note 45, at 228–29.

47 Most international exhaustion regimes permit parallel importation for products previously sold by the patent-holder or “with its permission” in

tend to provide less legal certainty to generic companies.

These early quasi-commercial licenses were followed by an increasing number of VLs with strengthened access provisions. As discussed further below, multiple factors appear to have been instrumental in the increased use of VLs:

1. Government pressure—whether based on political, legal (including threat of compulsory and government-use licenses,<sup>48</sup> use of the LDC pharmaceutical waiver,<sup>49</sup> and competition remedies), or industrial policy;
2. Rising use of patent opposition procedures<sup>50</sup> to weed out unworthy patents, particularly in India;
3. The belief by some academics, treatment providers, and civil society activists in the access community that TRIPS implementation, including the introduction of product patents in India,<sup>51</sup> and increased TRIPS-plus trade agreements and U.S./E.U. pressure, required resorting to voluntary licensing strategies;
4. The adoption of voluntary licensing by Gilead as a core

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another country. A smaller number of countries, including most famously Kenya, have adopted an international exhaustion rule that permits importation of products “lawfully” sold in another country. This latter rule would ordinarily permit parallel importation of medicines produced in compliance with a non-assertion/non-enforcement declaration or agreement. The rule is also interpreted to allow parallel importation of medicines produced pursuant to a compulsory license. See BROOK K. BAKER, PROCESSES AND ISSUES FOR IMPROVING ACCESS TO MEDICINES 21-24 (2004), [http://www.iprsonline.org/resources/docs/Baker\\_TRIPS\\_Flex.pdf](http://www.iprsonline.org/resources/docs/Baker_TRIPS_Flex.pdf).

48 TRIPS Agreement, *supra* note 16, provides for compulsory and government-use licenses in Article 31 and in recently adopted Article 31bis, and for judicially granted licenses in Article 44.2. See *WTO IP Rules Amended to Ease Poor Countries’ Access to Affordable Medicines*, WTO (Jan. 23, 2017), [https://www.wto.org/english/news\\_e/news17\\_e/trip\\_23jan17\\_e.htm](https://www.wto.org/english/news_e/news17_e/trip_23jan17_e.htm) (announcing the Article 31bis amendment to the TRIPS Agreement). Countries’ rights to adopt and use compulsory licenses were confirmed by the World Trade Organization, Ministerial Declaration of 14 November 2001, WTO Doc. WT/MIN(01)/DEC/2 (2001) [hereinafter Doha Declaration].

49 *TRIPS Report on Least Developed Country Members*, *supra* note 17.

50 Pre- and post-grant opposition procedures allow third parties to offer evidence and challenge patent eligibility in patent office examinations, which is much quicker and more affordable than judicial patent invalidation/revocation procedures.

51 India was required to become fully TRIPS compliant by 2005 as a country that had previously not allowed patents on pharmaceutical products. See TRIPS Agreement, *supra* note 16, art. 65, para. 4.

business strategy;

5. The decreased reliance by companies on product donations and tiered pricing, and recognition that voluntary licensing had some reputational and commercial (market-splitting) benefits in addition to their face-saving and precedential preference for voluntary versus involuntary measures; and
6. The establishment of the MPP, which facilitated and rationalized voluntary licensing practice and has since expanded beyond HIV to hepatitis C and tuberculosis.

The fact that governments have had the power to take TRIPS-compliant action to overcome IP barriers has been a substantial factor in the emergence of access VLs. The threat of compulsory licensing has also resulted in discount prices for some originator medicines.<sup>52</sup> Most commonly, VLs/non-assert agreements have been issued because of countries' TRIPS-compliant right to issue compulsory licenses<sup>53</sup> and in some cases as a direct result of compulsory licensing activities.<sup>54</sup> Compulsory licenses on pharmaceutical products—

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52 Jerry Wetzler et al., *Timeline for US-Thailand Compulsory License Dispute*, INFOJUSTICE 21 nn.23–24 & 38, 22 n.35 (Apr. 2, 2009), <http://infojustice.org/wp-content/uploads/2012/11/pijip-thailand-timeline.pdf>.

53 See Doha Declaration, *supra* note 48. The threat and practice of compulsory and government-use licenses is broader than commonly understood. Between 2001 and 2014, Ellen 't Hoen has documented: (1) 34 instances of compulsory licensing activity in 24 countries, not all of which necessarily resulted in the grant or implementation of a license, and (2) 51 instances of government-use. ELLEN 'T HOEN, PRIVATE PATENTS AND PUBLIC HEALTH: CHANGING INTELLECTUAL PROPERTY RULES FOR ACCESS TO MEDICINES 54–61 (Health Action Int'l 2016).

54 'T HOEN, *supra* note 53, at 71–72; Reed Beall & Randall Kuhn, *Trends in Compulsory Licensing of Pharmaceuticals Since the Doha Declaration: A Database Analysis*, 9 PLOS MED. 1 (2012), <http://journals.plos.org/plosmedicine/article/file?id=10.1371/journal.pmed.1001154&type=printable>; C. H. Unnikrishnan, *Compulsory Licences May Spur More Voluntary Licensing Deals*, LIVEMINT (Jan. 24, 2013, 11:01 PM), <http://www.livemint.com/Home-Page/f0R9060osU7bENFNwlnx5O/Compulsory-licences-may-spur-more-voluntary-licensing-deals.html>. See also Patralekha Chatterjee, *Gilead Solvaldi Case Reveals Patent-Health Fissures in India*, INTELL. PROP. WATCH (Sept. 3, 2016), <http://www.ip-watch.org/2016/03/09/gilead-solvaldi-case-reveals-patent-health-fissures-in-india/> (reporting D.G. Shah of the Indian Pharmaceutical Alliance as saying: “[w]e support provision for CL [compulsory license] to pre-empt abuse of monopoly. . . However, the CL route is full of thorns and uncertainties. VL [voluntary licensing] offered the same outcome without pain. We see in it a better solution than confrontation with Big Pharma.”).

except those that address emergencies, are limited to public non-commercial use, or redress competition violations—require the prospective licensee to engage in prior negotiations for a reasonable period of time and on reasonable commercial terms with the right holder before a compulsory license can be issued.<sup>55</sup> In the face of coercive government pressure to negotiate, right holders might choose to offer a voluntary license rather than face a government’s “involuntary” action.<sup>56</sup> A variant of compulsory license-related VLs are those granted under the threat of competition remedies, most famously the Treatment Action Campaign’s *Hazel Tau* case before the Competition Commission in South Africa.<sup>57</sup> Finally, as a result of the 32 times that 24 LDCs have invoked their rights under the TRIPS pharmaceutical waiver/extension,<sup>58</sup> they are always included in access licenses.

VLs have also been granted to countries’ private or state-owned companies, frequently in response to threats of compulsory or government-use licenses or price controls. Such licenses are often negotiated to further countries’ industrial development policy and might best be called industrial-policy licenses.<sup>59</sup> For example, in Brazil, such a license perpetuated the exclusive rights for a period of time in exchange for technology/know-how transfer to capacitate

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55 See TRIPS Agreement, *supra* note 16, art. 31.

56 This possibility also means that purely compulsory-license-based access strategies can sometimes result in voluntary licensing solutions, whether desired or not.

57 See BELINDA BERESFORD, *THE PRICE OF LIFE: HAZEL TAU AND OTHERS VS GLAXOSMITHKLINE AND BOEHRINGER INGELHEIM: A REPORT ON THE EXCESSIVE PRICING COMPLAINT TO SOUTH AFRICA’S COMPETITION COMMISSION* 35–37 (Jonathan Berger et al. eds., 2003); Mark Heywood, *South Africa’s Treatment Action Campaign: Combining Law and Social Mobilization to Realize the Right to Health*, 1 J. HUM. RTS. PRAC. 14, 14–36 (2009); *CPTech’s 2003 Reports for the RSA Competition Commission, in Hazel Tau et al. v GSK, Boehringer, et al*, KNOWLEDGE ECOLOGY INT’L, <https://www.keionline.org/competition/2003-hazel-tau-tac> (last visited June 17, 2018).

58 ‘T HOEN, *supra* note 53, at 61–65.

59 South African, Brazilian, and Indian companies have all received VLs that are at least partially grounded in industrial policy considerations. The legal basis for industrial policy licenses rests in part on the grounds of local working requirements in national patent law. It is beyond the scope of this article to detail the TRIPS-compliance of local working rules, which industry and U.S. trade policy abhor, but there are strong arguments that TRIPS does allow for compulsory licenses based in whole or in part on desire to develop local industry. See Marketa Trimble, *Patent Working Requirements: Historical and Comparative Perspectives*, 6 U.C. IRVINE L. REV. 483 (2016).

local manufacturers, but not always on the most favorable terms.<sup>60</sup> Unfortunately, Brazil's preference for local production seems to have resulted in higher medicine costs than best global prices.<sup>61</sup>

Increased deployment of VLs has also resulted from several other forces. One was India's transition to TRIPS compliance in 2005, when India was required to accept post-1994 pharmaceutical product patent applications and to tackle a large backlog of such applications in its TRIPS-mandated "mailbox."<sup>62</sup> However, as briefly mentioned above, India had also adopted opposition procedures, which allowed generic companies and other interested parties, including health activists and civil society organizations, to oppose patent applications at the pre- and post-grant stage.<sup>63</sup> India has used its opposition procedures on multiple occasions to oppose secondary "evergreening" patents on key medicines, including most famously Novartis' cancer medicine, Glivec.<sup>64</sup> One of the industry's responses

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60 See, e.g., *Civil Society Demands a Response from the Government in Relation to the Contract of ARV Drug Atazanavir*, GRUPO DE TRABALHO SOBRE PROPRIEDADE INTELECTUAL (Dec. 17, 2013), [http://deolhonaspateentes.org/media/file/notas%20GTPI%202013/release%20atazanavir\\_final%20\(english\).pdf](http://deolhonaspateentes.org/media/file/notas%20GTPI%202013/release%20atazanavir_final%20(english).pdf).

61 Constance Meiners et al., *Modeling HIV/AIDS Drug Price Determinants in Brazil: Is Generic Competition a Myth?*, PLoS ONE, Aug. 2011, at 1, 2, 5, <http://www.plosone.org/article/fetchObject.action?uri=info:doi/10.1371/journal.pone.0023478&representation=PDF>. Amy Nunn et al., *Evolution of Antiretroviral Drug Costs in Brazil in the Context of Free and Universal Access to Universal AIDS Treatment*, 4 PLoS MED. 1804, 1807–13 (2007), <http://www.plosmedicine.org/article/fetchObject.action?uri=info:doi/10.1371/journal.pmed.0040305&representation=PDF> (describing relatively higher generic prices in Brazil). For a more comprehensive discussion of Brazil's search for pharmaceutical autonomy, see MATTHEW FLYNN, *PHARMACEUTICAL AUTONOMY AND PUBLIC HEALTH IN LATIN AMERICA: STATE, SOCIETY AND INDUSTRY IN BRAZIL'S AIDS PROGRAM* (Routledge 2015).

62 TRIPS Agreement, *supra* note 16, art. 70, para. 8.

63 See WIPO Standing Comm. on the Law of Patents, *Opposition Systems and other Administrative Revocation and Invalidation Mechanisms*, U.N. Doc. SCP/18/4 (Apr. 3, 2012), [http://www.wipo.int/edocs/mdocs/scp/en/scp\\_18/scp\\_18\\_4.pdf](http://www.wipo.int/edocs/mdocs/scp/en/scp_18/scp_18_4.pdf). An early example of a successful use of opposition procedures was the efforts of AIDS activists in 2001 to oppose a patent application on didanosine in Thailand. See *AIDS Access Foundation v. Bristol-Myers Squibb Co.*, IP 93/2545, Black Case No. 34/2544, Red Case No. 92/2545, Central Intellectual Property & International Trade Court [Cent. Prop. & Int'l Trade Ct.] (Jan. 1, 2002) (Thailand), <http://www.asianlii.org/th/cases/THCIPITC/2002/1.html>.

64 Chan Park & Leena Menghaney, *TRIPS Flexibilities: The Scope of Patentability and Oppositions to Patents in India*, in *ACCESS TO KNOWLEDGE IN THE AGE OF INTELLECTUAL PROPERTY* 426 (Gaëlle Krikorian & Amy Kapczynski eds.,

to successful oppositions has been to increase negotiations of VLs. The Indian generics industry has been quite frank that accepting VLs with commercial potential may in many instances be superior to pursuing what may be costly and time-delayed opposition strategies.<sup>65</sup>

An additional factor in the expanded use of VLs is the emergence of Gilead as a major supplier of HIV and hepatitis medicines. Gilead acquired highly profitable and high volume second-generation ARVs, including tenofovir (TDF) and emtricitabine (FTC). It had no international sales and distribution systems at the time and was facing considerable pressure from AIDS activists on its pricing and licensing practices.<sup>66</sup> Gilead essentially decided to shed its direct sales aspirations in 95 LMICs and granted VLs to eight generic companies in India in 2006.<sup>67</sup> Those licenses contained several restrictive terms, including efforts to split and tie-up the market for APIs, to seek royalties on sales even when patents were not in force, and to prevent sales in unapproved markets even where TDF and FTC and their combinations are not patented.<sup>68</sup> These provisions resulted in a complaint to the Federal Trade Commission,<sup>69</sup>

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2010).

- 65 See Chatterjee, *supra* note 54 (reporting D.G. Shah of the Indian Pharmaceutical Alliance as saying: “We want the VL route to be adopted by more and more companies to provide access and create competition. It is the most effective way of reducing medicines prices. Hence, when the objective of access and affordability were addressed by VL, we had no reason to oppose.”).
- 66 DAVID BARON ET AL., GILEAD SCIENCES (A) THE GILEAD ACCESS PROGRAM FOR HIV DRUGS (Stan. Graduate Sch. of Bus. 2007), <https://www.gsb.stanford.edu/faculty-research/case-studies/gilead-sciences-gilead-access-program-hiv-drugs> (describing Gilead as having no international distribution system); Liz Highleyman, *Activists Protest Gilead*, THE BAY AREA REP. (May 18, 2006), <http://www.ebar.com/news/article.php?sec=news&article=845> (describing protest actions).
- 67 Press Release, Gilead Sciences, Inc., Gilead Announces Licensing Agreements with Eight India-Based Companies for Manufacturing and Distribution of Generic Versions of Viread in the Developing World (Sept. 22, 2006), <https://www.gilead.com/news/press-releases/2006/9/gilead-announces-licensing-agreements-with-eight-indiabased-companies-for-manufacturing-and-distribution-of-generic-versions-of-viread-in-the-developing-world>.
- 68 James Love, *Gilead Efforts to Control Global Market for Two AIDS Drugs*, HUFFINGTON POST: THE BLOG (Feb. 15, 2007, 9:36 AM, updated May 25, 2011), [https://www.huffingtonpost.com/james-love/gilead-efforts-to-control\\_b\\_41304.html](https://www.huffingtonpost.com/james-love/gilead-efforts-to-control_b_41304.html).
- 69 Press Release, Knowledge Ecology Int’l, KEI Asks FTC to Investigate Gilead Effort to Control Market for AIDS Drugs Ingredients (Feb. 15, 2007),



after which Gilead modified one of the challenged terms, removing prohibitions against licensees challenging patents.<sup>70</sup>

Starting in 2010, the MPP, financed and formed under the auspices of Unitaid,<sup>71</sup> began negotiating VLs, which it characterized as public health licenses because of their broad geographic scope, transparency, and preservation of TRIPS flexibilities. The basic business model of the MPP was to seek voluntary in-licenses on ARVs from multiple originators, and thereafter to grant multiple out-licenses to qualified generic producers to manufacture and sell individual and combination medicines, including novel pediatric and fixed dose combinations as needed. Initial reactions to MPP licenses with innovator companies, starting with Gilead, were mixed, some

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<https://www.keionline.org/book/access-to-medical-technologies/medical-diseases-conditions-and-technologies/keiasksftctoinvestigategileadefforttocontrolmarketforaidsdrugsingredients>.

70 Judit Rius, *Amendment to the Gilead-Ranbaxy License Agreement*, KNOWLEDGE ECOLOGY INT'L (June 9, 2008), <http://keionline.org/node/77>.

71 For early accounts of the founding of the MPP, see sources cited *supra* note 5. Patent pools for medicines were discussed by the World Health Assembly and referenced in WHO, *Global Strategy and Plan of Action on Public Health, Innovation and Intellectual Property* (2011), [http://www.who.int/phi/publications/Global\\_Strategy\\_Plan\\_Action.pdf](http://www.who.int/phi/publications/Global_Strategy_Plan_Action.pdf). Patent pools for medicines have been endorsed in WHO, Consultative Expert Working Grp. on Research & Dev.: Fin. & Coordination, *Research and Development to Meet Health Needs in Developing Countries: Strengthening Global Financing and Coordination*, at 56–57 (Apr. 2012), <http://apps.who.int/iris/bitstream/10665/254706/1/9789241503457-eng.pdf?ua=1>. Patent pools were discussed recently within the United Nations. See U.N. Secretary-General's High-Level Panel on Access to Med., *Promoting Innovation and Access to Health Technologies*, at 8, 10–11 (Sept. 2016), <https://static1.squarespace.com/static/562094dee4b0d00c1a3ef761/t/57d9c6ebf5e231b2f02cd3d4/1473890031320/UNSG+HLP+Report+FINAL+12+Sept+2016.pdf> (recommending that public funding agencies, universities, and research institutions should consider licensing their IP rights to public sector patent pools). In discussing the MPP, the High Level Panel Report praised its transparency and its enablement of treatment access, though it noted its narrow disease focus. *Id.* at 23. Three panel members did not agree that the solution to unaffordable price was expanding the MPP to all diseases. *Id.* at 55. One panel member opined that VLs, including those within the MPP, were undermining access to medicines in middle-income countries (MICs) and also creating tensions in the use and implementation of TRIPS flexibilities. *Id.* at 63. The Lancet Commission on Essential Medicines recommended that the remit of the MPP be expanded to include access to all essential medicines. Veronika J. Wirtz et al., *Essential Medicines for Universal Health Coverage*, 389 LANCET 403, 454–455, 460 (2017), [http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736\(16\)31599-9.pdf?code=lancet-site](http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(16)31599-9.pdf?code=lancet-site).



largely positive,<sup>72</sup> but others quite negative, including a proposal

72 More positive reviews that still entail critiques, especially concerning geographic scope, API provisions, and restrictions of licenses to Indian licensees include ‘T HOEN, *supra* note 53, at 73–77 (finding that the advantages include that licenses are negotiated from a public health perspective, have broad coverage, and are predictable and transparent); Beyer, *supra* note 45 (finding that MPP’s Gilead licenses compare relatively favorably to bilateral licenses granted by brand name companies); GOULDING & PALRIWALA, *supra* note 45, at 19–36 (finding that the MPP could be useful in achieving its stated access goals if it could gain participation from a critical mass of originator and generic companies); ACCESS TO MED. FOUND., *THE ACCESS TO MEDICINE INDEX 2014*, at 105, 109–10, 112 (2014) (finding that MPP licenses cover the broadest geographic scope and provide the largest degree of flexibility for licensees); Cox, *supra* note 5, at 317–19 (rejecting an “all or nothing” mentality and concluding that expanded geographical coverage, incentives for innovation, and improved licensing terms showed that the MPP was an improvement over the status quo); Brook K. Baker, *Inside Views: Corporate Self-Interest and Strategic Choices: Gilead Licenses to Medicines Patent Pool*, INTELL. PROP. WATCH (July 17, 2011), <http://www.ip-watch.org/2011/07/21/corporate-self-interest-and-strategic-choices-gilead-licenses-to-medicines-patent-pool/> [hereinafter *Inside Views*] (critiquing several provisions of the agreement but nonetheless concluding that: the licensed territory was significant; important pipeline medicines were included; combinations with non-Gilead products were allowed; transfer of technical know-how was permitted; pediatric use was royalty-free; referencing of regulatory data to fast-track registration of generic equivalents was permitted; and the field-of-use of the TDF license includes both HIV and hepatitis B prevention and treatment); James Love, *KEI Comment on the Medicines Patent Pool License with Gilead*, KNOWLEDGE ECOLOGY INT’L (July 11, 2011), <http://keionline.org/node/1184>; Krista Cox, *Medicines Patent Pool Agreement with Gilead Contains Flexibilities Including Termination Provisions and Severability of Licenses*, KNOWLEDGE ECOLOGY INT’L (July 26, 2011), <http://keionline.org/node/1192>; Posting of Brook K. Baker, b.baker@neu.edu, to ip-health@lists.keionline.org (July 26, 2011), [http://lists.keionline.org/pipermail/ip-health\\_lists.keionline.org/2011-July/015827.html](http://lists.keionline.org/pipermail/ip-health_lists.keionline.org/2011-July/015827.html); Posting of Brook K. Baker, b.baker@neu.edu, to ip-health@lists.keionline.org (Oct. 13, 2011), [http://lists.keionline.org/pipermail/ip-health\\_lists.keionline.org/2011-October/001411.html](http://lists.keionline.org/pipermail/ip-health_lists.keionline.org/2011-October/001411.html); James Love, *Coverage of Persons Living with HIV Included in Gilead MPP Licenses*, KNOWLEDGE ECOLOGY INT’L (Oct. 14, 2011), <http://keionline.org/node/1295>; *MSF Review of the July 2011 Gilead Licenses to the Medicines Patent Pool*, MÉDECINS SANS FRONTIÈRES, (Dec. 19, 2011), [https://www.msfacecess.org/sites/default/files/MSF\\_assets/HIV\\_AIDS/Docs/AIDS\\_Briefing\\_GileadLicenceReview\\_ENG\\_2011.pdf](https://www.msfacecess.org/sites/default/files/MSF_assets/HIV_AIDS/Docs/AIDS_Briefing_GileadLicenceReview_ENG_2011.pdf); Médecins Sans Frontières, *Untangling the Web of Antiretroviral Price Reductions: 15<sup>th</sup> Edition*, at 91–97 (July 25, 2012), [https://www.msfacecess.org/sites/default/files/MSF\\_assets/HIV\\_AIDS/Docs/AIDS\\_report\\_UTW15\\_ENG\\_2012.pdf](https://www.msfacecess.org/sites/default/files/MSF_assets/HIV_AIDS/Docs/AIDS_report_UTW15_ENG_2012.pdf); *We Need the Patent Pool to Work: A Joint Statement by Treatment Action Campaign, Treatment Action Group, HIV i-Base, European AIDS Treatment Group and SECTION27*, TREATMENT ACTION GROUP (Nov. 16, 2011), <http://www.treatmentactiongroup.org/press/2011/we-need-patent-pool/>; Posting by Jessica Hamer, JHamer@oxfam.org.uk, to

that the Gilead license be revoked and that the MPP and its sponsor Unitaid impose a moratorium on new licenses until improvements in key licensing terms were guaranteed.<sup>73</sup> Following these critiques

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healthgap@lists.mayfirst.org (Nov. 16, 2011), <https://lists.mayfirst.org/pipermail/healthgap/2011-November/003168.html>.

- 73 Some responses, especially from civil society formations in countries excluded from MPP licenses have been much more critical both with respect to process and substance, especially with respect to geographic coverage, API restrictions, licensee restrictions, including country of manufacture, arbitration and termination provisions, inclusion of pipeline products, and impacts on use of other access-to-medicines flexibilities. See, e.g., INT'L TREATMENT PREPAREDNESS COAL. & INITIATIVE FOR MEDS., *THE IMPLICATIONS OF THE MEDICINES PATENT POOL AND GILEAD LICENSES ON ACCESS TO TREATMENT: BRIEFING PAPER* (2011), <http://www.i-mak.org/wp-content/uploads/2017/10/ITPCI-MAK-TheBroaderImplicationsoftheMPPandGileadLicensesonAccess-FINAL25-7-2011.pdf> (calling the outcome “a serious setback for the global movement on access to medicines” and calling for a “censure” of the agreement and a moratorium on future MPP license negotiations); INT'L TREATMENT PREPAREDNESS COAL., *A REPORT ON A CONSULTATION BETWEEN CIVIL SOCIETY REPRESENTATIVES AND THE MEDICINE PATENT POOL/UNITAID: THE MPP-GILEAD LICENSE AGREEMENT* (2011) (on file with author) [hereinafter *REPORT ON A CONSULTATION BETWEEN CIVIL SOCIETY REPRESENTATIVES AND THE MEDICINE PATENT POOL/UNITAID*]; Int'l Treatment Preparedness Coal., *Concerns About the Process, Principles of Medicines Patent Pool and the Licence* (Oct. 10, 2011) (on file with author); INT'L TREATMENT PREPAREDNESS COAL. & INITIATIVE FOR MEDS., *FINANCIAL IMPACT OF MEDICINES PATENT POOL: I-MAK/ITPC COUNTER ANALYSIS* (2011), <http://apps.who.int/medicinedocs/documents/s19792en/s19792en.pdf>; INT'L TREATMENT PREPAREDNESS COAL. & INITIATIVE FOR MEDS., *ACCESS & KNOWLEDGE, FINANCIAL IMPACT OF MEDICINES PATENT POOL: I-MAK/ITPC COUNTER ANALYSIS* (2011), [http://static1.1.sqspcdn.com/static/f/129694/14585606/1318369678653/FINAL+Financial+Impact+of+MPP+-+I-MAK-ITPC+Counter+Analysis\\_2+Oct+2011+1.pdf?token=rs%2F1Zjgc9zmKJBOiKJbh%2Bja%2FZgl%3D](http://static1.1.sqspcdn.com/static/f/129694/14585606/1318369678653/FINAL+Financial+Impact+of+MPP+-+I-MAK-ITPC+Counter+Analysis_2+Oct+2011+1.pdf?token=rs%2F1Zjgc9zmKJBOiKJbh%2Bja%2FZgl%3D); *Open Letter from Thai Civil Society: One Step Forward, Two Steps Back: The Agreement Between the Medicines Patent Pool and Gilead Sciences, Inc.*, DON'T TRADE OUR LIVES AWAY (July 21, 2011), <https://donttradeourlivesaway.wordpress.com/2011/07/22/open-letter-from-thai-civil-society-one-step-forward-two-steps-back-the-agreement-between-the-medicine-patent-pool-and-gilead-sciences-inc/>; Posting of Renata Reis, [renata@abiuids.org](mailto:renata@abiuids.org), to [ip-health@lists.keionline.org](mailto:ip-health@lists.keionline.org) (July 20, 2011, 16:25 EDT), [http://lists.keionline.org/pipermail/ip-health\\_lists.keionline.org/2011-July/001142.html](http://lists.keionline.org/pipermail/ip-health_lists.keionline.org/2011-July/001142.html); Sangeeta Shashikant & K. M. Gopakumar, *Gilead Grants License to Medicines Pool, Devil is in Details*, PEOPLE'S HEALTH MOVEMENT (July 28, 2011), <http://www.phmovement.org/en/node/6097>; *Lawyers' Collective letter to the UNITAID Board* (Dec. 10, 2011) (on file with author); INT'L TREATMENT PREPAREDNESS COAL. & INITIATIVE FOR MEDS., *VOLUNTARY LICENSING: OPTIMIZING GLOBAL EFFORTS AND MEASURING IMPACT* (2012), <http://apps.who.int/>

and further negotiations with the MPP, Gilead ultimately agreed to modify provisions clarifying its non-enforcement agreement on FTC and the right of licensees to become compulsory licensees.<sup>74</sup> Subsequently, Gilead also amended its licenses in 2014 and 2015 to allow API and final product manufacturing in China, not just India, and to also allow final product manufacturing in South Africa. In addition, it amended its licenses to include patents on Tenofovir Alafenamide (TAF) and TDF/FTC/EFV<sup>75</sup> and again in 2017 to expand the geographic scope of its ARV licenses to include Malaysia, the Philippines, Ukraine, and Belarus, and to add a new ARV, bicitegravir (BIC).<sup>76</sup>

By most accounts, the MPP has had substantial public health impacts, most deriving from the Gilead license. According to its own reporting, “As of January 2018, the MPP has signed agreements with nine patent holders for thirteen HIV antiretrovirals, one HIV technology platform, one tuberculosis treatment and two hepatitis C direct-acting antivirals. Twenty generic manufacturers and product developers have now signed MPP sublicensing agreements.”<sup>77</sup> The

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medicinedocs/documents/s19791en/s19791en.pdf.

- 74 Posting of Kaitlin Mara, [kmara@medicinespatentpool.org](mailto:kmara@medicinespatentpool.org), to [ip-health@lists.keionline.org](mailto:ip-health@lists.keionline.org) (Nov. 22, 2011, 11:40 PST), [http://lists.keionline.org/pipermail/ip-health\\_lists.keionline.org/2011-November/016211.html](http://lists.keionline.org/pipermail/ip-health_lists.keionline.org/2011-November/016211.html).
- 75 Press Release, Meds. Patent Pool, The Medicines Patent Pool (MPP) Broadens Collaboration with Gilead Sciences: Signs License for Phase III Tenofovir Alafenamide (TAF) (July 23, 2014), <https://medicinespatentpool.org/mpp-media-post/the-medicines-patent-pool-mpp-broadens-collaboration-with-gilead-sciences-signs-licence-for-phase-iii-medicine-tenofovir-alafenamide-taf/>; Press Release, Meds. Patent Pool, The Medicines Patent Pool and Gilead Sciences Expand Licenses to Allow Generic Manufacture of Medicines in South Africa (June 11, 2015), <http://www.medicinespatentpool.org/the-medicines-patent-pool-and-gilead-sciences-expand-licence-to-allow-generic-manufacture-of-medicines-in-south-africa/>.
- 76 Press Release, Gilead Sci., Inc., Gilead Announces New License Agreement with the Medicines Patent Pool for Access to Bicitegravir (Oct. 4, 2017), <http://www.gilead.com/news/press-releases/2017/10/gilead-announces-new-license-agreement-with-the-medicines-patent-pool-for-access-to-bicitegravir>.
- 77 *Update On Progress Of Sublicenses*, MEDS. PATENT POOL, <https://medicinespatentpool.org/what-we-do/global-licence-overview/update-on-progress-of-mpp-sublicensees/> (last visited June 17, 2018). Details of then current licenses can be found at *License Overview*, MEDS. PATENT POOL, <https://medicinespatentpool.org/what-we-do/global-licence-overview/> (last visited June 17, 2018). Since this update, five additional generic licensees from South Africa, India, China, and South Korea have signed sublicensing agreements. Press Release, Meds. Patent Pool, The Medicines Patent Pool Adds New Suppliers from South Africa and South Korea to Its Growing Generic

impact of MPP Agreements on HIV and hepatitis C treatment access, pricing, and savings through June 2017 include distribution of generics totaling 14.6 million treatment years in 125 countries with an average price drop of 89% and with \$391 million in cost savings.<sup>78</sup> With respect to HIV products alone, there have been \$273 million in direct savings in MPP's expanded territories through December 2016 and a projected \$2.3 billion in savings through 2028, with a cost-benefit ratio of MPP's operating budget to direct savings of 1:43.<sup>79</sup>

The geographical scope of MPP licenses includes both countries/territories directly identified as within the license and, in some cases, additional indirect coverage where the license permits immediate marketing and distribution to countries where no patent is in force (for further discussion see subsections IV.D.1 and IV.D.2, *infra*). This coverage is substantial for LMICs, especially for its HIV and Tuberculosis licenses. Coverage in LMICs is highest for Tuberculosis and HIV pediatric medicines but lower for HIV and significantly lower for hepatitis C. Despite relatively broad coverage, millions of people living with HIV and tens of millions living with hepatitis C in certain MICs cannot source lower cost generic equivalents from MPP licensees.

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Manufacturing Network (May 2, 2018), <https://medicinespatentpool.org/mpp-media-post/the-medicines-patent-pool-adds-new-suppliers-from-south-africa-and-south-korea-to-its-growing-generic-manufacturing-network/>.

78 MEDS. PATENT POOL, UPDATE ON PROGRESS OF MPP SUBLICENSES 20 (2018), <https://medicinespatentpool.org/uploads/2017/09/Update-on-Progress-of-MPP-Sub-licensees-January2018.pdf>.

79 Sandeep Juneja et al., *Projected Savings Through Public Health Voluntary Licences of HIV Drugs Negotiated by the Medicines Patent Pool (MPP)*, PLoS ONE, May 25, 2017, <http://journals.plos.org/plosone/article/file?id=10.1371/journal.pone.0177770&type=printable>.

**Table 1: Effective Direct and Indirect Coverage of MPP Licenses in Low- and Middle-Income Countries<sup>80</sup>**

Pharmaceutical Companies	Medicine	Effective Direct and Indirect Coverage in LMICs
AbbVie	Lopinavir/ritonavir (LPN/r, an HIV ARV)	78.9%
	Lopinavir/ritonavir (LPN/r pediatric)	98.8%
Bristol-Myers Squibb	Atazanavir (ATV, HIV)	89%
	Daclatasvir (DAC, HVC)	65.4%
Gilead	Bictegravir (BIC, HIV)	89.8%
	Cobicistat (COBI, HIV)	89.8%
	Elvitegravir (EVG, HIV)	88.4%
	Emtricitabine (FTC, HIV)	89.8%
	Tenofovir Alafenamide (TAF, HIV)	89.8%
Merck Sharp & Dohme ViiV Healthcare	Tenofovir disoproxil fumarate (TDF, HIV)	89.8%
	Raltegravir (RAL, pediatric HIV)	98%
	Dolutegravir (DTG, HIV)	90%
	Dolutegravir (DTG, pediatric)	99%
	Research Institutions	
John Hopkins	Sutezolid (TB)	100%

<sup>80</sup> *License Overview*, MEDS. PATENT POOL, *supra* note 77. More details of licenses' direct territorial coverage can be found on individual license pages accessed from *Products Licensed*, MEDS. PATENT POOL, <https://medicinespatentpool.org/what-we-do/global-licence-overview/licences-in-the-mpp/> (last visited June 17, 2018).

In addition to significant cost savings and expanded country coverage in MPP access licenses, the MPP has become increasingly successful in incentivizing new formulations, either pediatric or adult. The MPP has helped launch the Paediatric HIV Treatment Initiative,<sup>81</sup> and its licenses have helped Drug for Neglected Diseases *initiative* (DNDi) and generic innovators to develop at least one new pediatric formulation.<sup>82</sup> For adults, its licenses have allowed novel co-formulation of TDF/lamiduvine (3tC)/efavirenz (EFV) and more recently TAF/3tC/EFV. Its most significant contribution to new adult formulations is the combination of dolutegravir (DTG), 3tC, and TDF, a fixed-dose combination that will not be available in high-income countries. This important new fixed-dose combination, which is more efficacious, more durable, less toxic, and cheaper, will be available for sale in at least 92 countries. The MPP is continuing to support the development of additional pediatric and adult formulations, and it has also entered into a development license for new nanotechnologies that might eventually result in significantly improved formulations.<sup>83</sup> But overall, progress in promoting incremental innovation in new formulations by MPP licensees, other than combinations, has been scant.

After this brief history of the emergence of access licenses and introduction to the MPP, it is time to analyze key licensing provisions and to identify best practices and make recommendations concerning access where appropriate.

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81 Press Release, Meds. Patent Pool, Paediatric HIV Treatment Initiative (PHTI) to Spur Innovation and Access to Improve the Lives of Children Living with HIV (May 19, 2014), <https://medicinespatentpool.org/mpp-media-post/paediatric-hiv-treatment-initiative-phiti-to-spur-innovation-and-access-to-improve-the-lives-of-children-living-with-hiv/>.

82 Press Release, Drugs for Neglected Diseases Initiative, Child-friendly Formulation of WHO-recommended Treatment Now Approved by the U.S. FDA for Children Living with HIV (June 3, 2015) <https://www.dndi.org/2015/media-centre/press-releases/pr-phiti-fda-approval-pellets/>.

83 E-mail from Esteban Burrone, Head of Policy, Medicines Patent Pool, to author (May 14, 2018) (on file with author) (referencing adult TAF/FTC/DTG and pediatric ABC/3tC/EFV). Press Release, Meds. Patent Pool, The Medicines Patent Pool Signs a Collaborative Agreement with the University of Liverpool to Develop HIV Nanomedicines (Dec. 1, 2015), <https://medicinespatentpool.org/mpp-media-post/the-medicines-patent-pool-signs-a-collaborative-agreement-with-the-university-of-liverpool-to-develop-hiv-nanomedicines/>.



## IV. Analysis of Significance and Impact of Specific Terms and Conditions in VLs

### A. IP Rights Included in the License

#### 1. Patent Rights

The most obvious IP rights that are licensed in VLs are patent rights. Typically, a fully effective VL will license all patents and patent applications, granted, pending, or under appeal. Such a license may include related divisions, selections, continuations, and amendments of the same, that might otherwise block generic production. Occasionally, these licenses might even reference future, related patents affecting the specific medicine. Not all patents granted on a medicine will necessarily block generic production, as some patent thickets are porous and some process patents can be invented around. But generic companies seeking a VL ordinarily prefer unfettered freedom to operate with respect to all patents that might arguably be infringed now or in the future by otherwise unauthorized manufacture, distribution, importation, and sale.

As discussed further in subsection IV.D.2, *infra*, the definition of licensed patents has another possible impact in supplying countries that are excluded from the license territory. Insufficient inclusion of granted, pending, and related future patents to be licensed could reduce rights to supply certain non-territory markets. For example, some MPP licenses allow licensees to supply non-territory markets “indirectly” when such supply does not infringe patents in the country of production/export and import/use.

*Recommended standard: Public health oriented licenses can and arguably should include all related patents, pending, granted, appealed, and future, that might adversely impact freedom to operate.*

#### a. “Weak” patent rights

There are differing opinions on whether patents that are “weak,”<sup>84</sup> patents on uses, pending patents, and patent denials

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84 Some standard-setting patent pools have had independent expert analysis of the essentialness of patents to avoid competition harms. Jorge L. Contreras, *Essentiality and Standards-Essential Patents*, CAMBRIDGE HANDBOOK OF TECHNICAL STANDARIZATION LAW – ANTITRUST, COMPETITION AND PATENT LAW (forthcoming Spring 2017). Some critics have suggested that the MPP should independently evaluate the merits of patents before taking a



under appeal should be included in licenses or not. Some critics argue that including such putative patent interests in licenses indirectly supports weak standards of patentability, undermines the rigor of patent examination, and provides an unjustifiable basis for territorial restrictions and royalty payments.<sup>85</sup> Although some of these questions are addressed further below, the most important pragmatic question is what effects such weak patents and patent applications have on the willingness of generic companies to produce medicines in the absence of a license. In the shadow of such patent claims, most generics are risk averse and want to avoid costly patent litigation<sup>86</sup> in multiple jurisdictions. Until finally and irrevocably terminated, the patent types listed above can cause the prudent generic company to avoid the risk of present or future infringement damages and litigation costs. Admittedly, some generic companies will risk infringing weak patents figuring that they will not face any infringement claims or that they might win any eventual challenge and that the economic returns are worth the costs of litigation. Some companies might choose to oppose a weak patent application in patent office proceedings or risk selling products that might fall within an ungranted patent and result in patent compensation claims once the patent is granted. However, these approaches seem to be the exception rather than the rule—the general rule is that generics want freedom to operate free of present or future infringement risk.

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license on them, a position the MPP rejected. REPORT ON A CONSULTATION BETWEEN CIVIL SOCIETY REPRESENTATIVES AND THE MEDICINE PATENT POOL/UNITAID, *supra* note 73, at 7–9. Obviously, such expert determinations are complex, expensive, and perhaps contested. They could also create false assurances. More to the point, in the absence of liability for a negligent freedom-to-operate opinion, generic companies might be unwilling to rely on the same, and would prefer inclusion of such patents within the MPP.

85 See sources cited *supra* note 73. The problem of poor quality patents is not the fault of VLS—it is a consequence of weak patentability criteria, poor patent examination, and perverse incentives rewarding examiners for granting patents and rewarding patent fees to patent offices. This problem should be proactively addressed through patent law reform adopting strict standards of patentability and disclosure, through better training and expanded capacity for good quality patent examination, and through elimination of pro-patenting incentives in patent offices.

86 Although patent litigation costs in the U.S. are falling because of inter partes review, they still average \$1.7 million in the U.S. in cases with \$1 million to \$10 million in controversy. Malathi Nayak, *Cost of Patent Infringement Litigation Falling Sharply*, BLOOMBERG L. (Aug. 10, 2017), <https://www.bna.com/cost-patent-infringement-n73014463011/>.

Even though this conclusion seems sound, it is different from the question of whether ungranted patents or appealed patent denials should justify territorial restrictions and/or royalty payments where such payments might not otherwise be due. Here, considerations are tempered by pragmatism. Fortunately, there are some best practices where only granted patents are cited as the basis for territorial restrictions and collection of royalties, e.g., the ViiV-MPP Adult DTG sublicense<sup>87</sup> and the BMS-MPP ATV license.<sup>88</sup> Better yet, the ViiV license also forgoes royalty payments based on patent status in the country of production and instead royalties are collected only on the basis of granted royalties in the country of importation and use.<sup>89</sup> Gilead, in contrast, collects royalties in all covered territories, based on granted, pending, or appealed patents and does so in part based on its control of the specific countries of manufacture where patents rights as defined remain in force.<sup>90</sup>

#### b. Inclusion of pending patents and patent denials under appeal

As a purely doctrinal question, where no exclusive rights have been granted, the basis for restricting generic production and immediately collecting royalties is thin. Conversely, as a pragmatic matter, at least in some jurisdictions, generics that have notice of pending patent applications and their potential infringement

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87 See Adult Sublicense Agreement Form cl. 2.3(b), MEDS. PATENT POOL (Apr. 2014), <https://medicinespatentpool.org/uploads/2014/04/ViiV-MPPF-DTG-Adult-Sublicense-form-Adult11.pdf> [hereinafter ViiV-MPP Adult Sublicense Agreement Form]; see also *id.* at app. B (list of royal-free countries).

88 Bristol-Myers Squibb Co. & Meds. Patent Pool License and Technology Transfer Agreement §§ 2.7(c), 3.1(a), MEDS. PATENT POOL (Dec. 11, 2013), <https://medicinespatentpool.org/uploads/2017/07/MPP-License-and-technology-transfer-agreement-Signed22.pdf> [hereinafter BMS-MPP Agreement]. Note: there is an exception to this right in the Bristol-Meyers Squibb (BMS) license if the sub-licensee relies on Licensed Manufacturing Know-How. *Id.*

89 ViiV-MPP Adult Sublicense Agreement Form, *supra* note 87, § 3.1, at 9.

90 Baker, *Inside Views*, *supra* note 72; see Gilead Sci. & Meds. Patent Pool [First/Second/Third] Amended and Restated License Agreement for Existing Licensees in India, § 1, MEDS. PATENT POOL (June 2017), <https://medicinespatentpool.org/uploads/2014/07/MPP-Sublicense-Agreement-for-Existing-Licensees-in-India-appendix-6-A-Form-June-2017.pdf> [hereinafter Gilead-MPP Restated License Agreement in India] (defining “Patents” as covering all patents and applications including future owned or controlled patents in the territory); *id.* § 10.3(c) (referencing that with respect to patents and patent applications, only patents held invalid or unenforceable are without any right of future appeal).

face retroactive patent infringement/damage claims under the “provisional rights” doctrine.<sup>91</sup> However, even if they will not face retroactive infringement penalties, generic companies are often loathe to make multi-million dollar up-front investments in product development, capacity expansion, product registration, and marketing and distribution if their production could be shut down by a future grant of a patent or the reversal of a patent denial on appeal. In this regard, the pending patent offers almost as much de facto exclusionary power to a patent applicant as does a granted patent.

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91 For example, in the U.S., a generic company would be subject to reasonable royalty claims for making, using, selling, offering to sell, or importing “infringing” products if the infringer received actual notice of the potential infringement for a use substantially identical to the claimed invention once the patent has been granted. 35 U.S.C. § 154(d) (2012); *see* Sharick Naqi, *Comment on Provisional Patent Rights*, 10 NW. J. TECH. & INTELL. PROP. 595 (2012). The similar remedy of reasonable compensation for pre-grant infringement applies in Canada. *See* Patent Act, R.S.C. 1985, c. P-4 s. 55(2) (2017) (Can.). Similar remedies are reportedly available in Australia, Brazil, China, France, Germany, India (may be contested), Italy, Japan, Malaysia, Russia, South Korea, Spain, Sweden, Taiwan, the United Kingdom, and Vietnam. Carlos O. Mitelman, *Blog: Protection of Patent Applications Pre-grant*, INT’L L. OFF. (Oct. 15, 2007), <http://www.internationallawoffice.com/newsletters/detail.aspx?g=85fa48e4-e3b1-4794-a3aa-e7dfcbb676d>; MATTHEW CUTLER, INTERNATIONAL PATENT LITIGATION SURVEY: A SURVEY OF PATENT CHARACTERISTICS IN 17 INTERNATIONAL JURISDICTIONS (2008) (on file with author).

<b>Advantages of including pending and appeal patents</b>	<b>Disadvantages of including pending and appeal patents</b>
<p>Generics are typically reluctant to manufacture and compete where there are pending patent claims both because of the risk of sunk costs in the event the patent is granted, and because of the risk in some countries of retroactive liability/damages for infringement once the patent is granted.</p> <p>It is easier to aggregate a larger market (since countries with pending patents are included), thus potentially accelerating robust competition and achievement of economies-of-scale.</p> <p>It is easier to gain access to new medicines than with compulsory licenses because many countries limit compulsory licenses to granted patents.</p> <p>It may be easier/quicker to gain access to new medicines than through opposition procedures which can drag out in time via appeals and which are not available in all LMICs; relevant expertise for oppositions is also not available in all LMICs.</p> <p>There is guaranteed access to new medicines/technologies early in the product life, which can lead to quicker manufacture and registration in LMICs.</p> <p>If co-formulation is allowed, earlier access to dependent fixed-dose combinations can have a license term terminating royalty rights, sector limitations, and other restrictive clauses in the event the patent is not granted or is revoked.</p> <p>Liceses can have a license term terminating royalty rights, sector limitations, and other restrictive clauses in the event the patent is not granted or is revoked.</p>	<p>Originators gain licensing/contractual control over generic licenses on more favourable terms than might be true for compulsory licenses.</p> <p>It probably reduces incentives for generic companies to oppose pending patents since access to significant LIC and LMIC markets already achieved.</p> <p>Royalty fees paid on pending patents, usually without provision for rebate in the case that the patent is not granted or is revoked.</p> <p>It is easy for the right holder to continue to file divisional and evergreening patents to keep putative exclusivity claims alive.</p> <p>It reduces the incentives for generic companies to seek or governments to issue compulsory licenses, especially when the issuing country/territory is already included in the VL; the potential gain of more liberal access via a compulsory license may not be worth the political expense of issuing a compulsory license.</p>

**c. APIs patent rights and restrictions**

Access to patents on final product formulation and essential processes is, of course, desirable, but at least in some contexts it is

also necessary to secure access to patents on active pharmaceutical ingredients. Where such patents exist, however, and even in some situations where they do not, some originators seek to exercise anti-competitive control over API supply via API patent rights. These issues are discussed at greater length in subsection IV.C.1., *infra*.

#### d. Patents on pipeline products

Traditionally, people needing medicines in LMICs have had to wait many years before they gain access to medical innovations and medicines introduced far earlier in rich countries and to rich patients. Delayed access to newer and improved medicines that are more efficacious, more tolerable and safer, more durable with respect to resistance, and potentially more affordable has significant individual and public health consequences. Therefore, one of the potential benefits of access licenses is earlier access to promising novel or improved therapies.<sup>92</sup> Naturally, there is a question of when it is appropriate to license promising pipeline medicines to promote access. Presently, one good practice entails licensing once Phase III clinical trials are undertaken. Licensing promising late-stage development products can mean that generics can begin product development and preparation of registration dossiers in anticipation of eventual product approval. In any event, generic medicines will not be permitted to enter the market until approval of the originator product<sup>93</sup> and corresponding regulatory approval of the generic equivalent because of common licensing terms to that effect.<sup>94</sup> The

92 The MPP has a well-developed set of criteria for prioritizing pipeline ARVs for licensing that include efficacy, safety and tolerability, durability, convenience and adherence, suitability for specific subpopulations, potential for pre-exposure prophylaxis, and potential to fill other public health gaps. MEDS. PATENT POOL & UNITAID, PRIORITIZATION OF HIV AND HEPATITIS C MEDICINES FOR IN-LICENSING TO THE MEDICINES PATENT POOL 5-7 (2017), [https://medicinespatentpool.org/uploads/2017/07/MPP-Prioritization-of-HIV-and-HCV-Medicines-for-In-Licensing\\_V6.pdf](https://medicinespatentpool.org/uploads/2017/07/MPP-Prioritization-of-HIV-and-HCV-Medicines-for-In-Licensing_V6.pdf).

93 See, e.g., Restated License Agreement in India, MEDS. PATENT POOL § 5(b) (2017), [https://medicinespatentpool.org/uploads/2017/10/MPP-2nd-AR-License-Amendment-1-Appendix-8-A\\_6.11.17.pdf](https://medicinespatentpool.org/uploads/2017/10/MPP-2nd-AR-License-Amendment-1-Appendix-8-A_6.11.17.pdf) (amending § 2.5(b) (ii) of the existing agreement).

94 See, e.g., Gilead-MPP Restated License Agreement in India, *supra* note 90, § 6.2. Section 6.2 states:

Manufacturing Requirements: (a) Minimum Standards. Licensee agrees that it shall manufacture API and Product in a manner consistent with (i) the applicable Indian manufacturing standards; (ii) either World Health Organization (“WHO”) pre-qualification standards, standards of the European Medicines Agency (“EMA”),

MPP has recently received licenses to technologies further upstream in the innovation pipeline on a promising hepatitis C direct acting antiviral and on a formulation nanotechnology.<sup>95</sup>

Some critics of VLs have expressed concerns that new therapies should not be licensed prematurely and specifically that medicines should not be licensed until the originator product receives marketing approval. Specifically, there were concerns about the pipeline product in Gilead's MPP license, cobicistat (COBI), arguing that it was not superior to ritonavir, whose base patent was soon to expire, and that Gilead's COBI patent was "weak."<sup>96</sup> It is fair to note that the patent on COBI is still pending eight years after filing in India. Similarly, although opposition to Gilead's COBI patents was recommended,<sup>97</sup> there is no publically available record of such an opposition having been filed.<sup>98</sup>

*Recommended standard: Public health voluntary licensing should allow early licensed access to promising new pipeline medicines, but final licensing or marketing of generic equivalents should be conditioned on marketing approval (product registration) of the medicine.*

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or United States Food and Drug Administration ("FDA") tentative approval standards ("Minimum Quality Standards"); and (iii) on a country-by-country basis, any applicable national, regional or local standards as may be required by the specific country where Product is sold.

*Id.* (emphasis removed).

95 Pharco Pharm., Inc. & Meds. Patent Pool License Agreement, MEDS. PATENT POOL (Apr. 20, 2017), <https://medicinespatentpool.org/uploads/2017/09/Licence-Pharco.pdf> [hereinafter Pharco-MPP Ravidasvir License]; Univ. of Liverpool & Meds. Patent Pool License Agreement, MEDS. PATENT POOL (Nov. 24, 2015), <https://medicinespatentpool.org/uploads/2017/07/MPP-University-of-Liverpool-Licence-Agreement-execution-copy.pdf> [hereinafter University of Liverpool-MPP Nanotechnology License].

96 See sources cited *supra* note 73.

97 INITIATIVE FOR MEDS. ACCESS & KNOWLEDGE, THE ROADMAP: THE HIV DRUG PIPELINE AND ITS PATENTS 15–16 (April 2013), [http://static1.1.sqspcdn.com/static/f/129694/22423698/1368647493727/HIV+Roadmap\\_11Apr2013\\_FINAL.pdf?token=uVsgh7k1CHeaonJLObcoaiVWm0%3D](http://static1.1.sqspcdn.com/static/f/129694/22423698/1368647493727/HIV+Roadmap_11Apr2013_FINAL.pdf?token=uVsgh7k1CHeaonJLObcoaiVWm0%3D).

98 See *Patent Opposition Database*, MSF ACCESS CAMPAIGN, <https://www.patentoppositions.org/> (last visited June 10, 2018).

Advantages of licensing pipeline products	Disadvantages of licensing pipeline products
<p>Early licensing of promising candidate/pipeline medicines gives incentives to generic companies to begin product development and preparation of follow-on registration dossiers.</p> <p>Completion of some of these activities even before final regulatory approval of the originator product means that generic equivalents can come to market much quicker.</p> <p>Early product introduction can have, but does not necessarily have, significant public health benefits depending on the safety, efficacy, durability, tolerability, and ease-of-use of the new product.</p> <p>The availability of more affordable and sufficient prospective quantities of new generic equivalents can be influential in global (WHO) treatment guidelines and in inclusion of newer medicines in national treatment guidelines.</p>	<p>Generic companies could waste time on pipeline medicine product development if the medicine is not in fact registered or if its placement in treatment guidelines is misjudged.</p> <p>There are arguments for and against early product introduction, but newly registered medicines have often been tested on small and select populations and for only a short period of time. Women, children, different age groups, and people with co-morbidities and who take other medicines are not routinely studied. Thus post-marketing pharmacovigilance can uncover dangerous and previously unknown side effects and contra-indications meaning that putting large populations on new, relatively untested medicines can have adverse rather than positive health impacts.</p>

#### e. Field-of-use

When licensing patent rights, the patent holder can define and restrict the permitted uses of the patented product or process by the licensee.<sup>99</sup> A licensor can grant unfettered, open “field-of-use” permission with respect to licensed patents. Alternatively, the patent holder can impose restrictions on field-of-use, including, in the context of medicines, restrictions as to diseases covered, formulations, and age groups. Field-of-use can also expressly permit research on or with the patented technology.

<sup>99</sup> See generally Thomas C. Meyers, *Field-of-Use Restrictions as Precompetitive Elements in Patent and Know-How Licensing Agreements in the United States and the European Communities*, 12 Nw. J. INT’L L. & BUS. 364 (1991).



- i. All other and newly approved uses vs. single disease use

Licensors can choose to license a medicine for a single therapeutic use, e.g., the treatment of HIV,<sup>100</sup> or it can license it more broadly to allow other medical uses.<sup>101</sup> Although there had been some early criticism with respect to permissible uses beyond a single-disease focus and concerns that field-of-use permission with respect to other uses might indirectly support “new use” patents, this critique has been substantially rebutted.<sup>102</sup> As a technical matter, substantive grounds for new use patents is set in national law and patenting guidelines and should be determined without reference to VLs. If patent examiners irrationally consider voluntary licensing standards, that should be addressed through training and proper examination incentive systems.

Allowing broad use has many advantages. It makes it much easier for generic producers, procurement and supply systems, prescribers, pharmacists, and patients who do not have to worry about field-of-use violations for generic equivalents. Otherwise, if some uses were not allowed, it would be a potential license violation for a medicine to be sold and consumed for a non-covered use.<sup>103</sup> Similarly, larger volume sales can result in increased market size, increased incentives for generic entry, and improved economies-of-scale, hopefully resulting in more affordable medicines. A related question is whether multiple use should be for uses specifically approved by a medicines regulatory authority or any use, even an off-label use.

*Recommended standard: Access licenses should allow all approved medical uses, or alternatively all medical uses, which would thereby allow prescribing of generic equivalents even for off-label uses.*

100 Merck, Sharp & Dohme’s (MSD) sub-license on Raltegravir is restricted to the treatment of HIV. Medicines Patent License Agreement with Merck, Sharp & Dohme Corp., MEDS. PATENT POOL § 1.5, <https://medicinespatentpool.org/uploads/2017/07/MPP-Merck-SL-Form-RAL.pdf> (last visited June 12, 2018) [hereinafter MSD-MPP License Agreement].

101 Gilead’s licenses do not contain any restriction on the therapeutic use of licensed medicines. “‘Field’ shall mean with respect to a particular Product any use that is consistent with the label approved by the FDA or applicable foreign regulatory authority in the countries of sale for the use of such Product.” See, e.g., Gilead-MPP Restated License Agreement in India, *supra* note 90, § 1.

102 Cox, *supra* note 5, at 306; MSF Review of the July 2011 Gilead Licenses to the Medicines Patent Pool, *supra* note 72, at 7–8.

103 A separate but related problem might be that such sale and use might violate an unlicensed use or method-of-use patent on the excluded indication.

Advantages of broad uses	Disadvantages of broad uses
<p>Advanced approval of a licensed product's availability to treat all relevant health conditions, present and future, can make the license much more attractive to generic producers.</p> <p>When new uses expand sales in the future, there can be additional incentives for generic entry and more efficient economies-of-scale, potentially resulting in lower prices.</p> <p>The burdens on producers, procurers, prescribers, pharmacists, and patients are all reduced if there are no questions about permissible uses of a previously registered licensed equivalent.</p> <p>Licensed permission with respect to new uses has no relevance whatsoever to the question of whether patents should be granted for new uses. That is a question for national patent law reform banning new uses licenses, with such bans being completely lawful under the TRIPS agreement. In such circumstances, banning new use patents would have the additional advantage of preventing evergreening and the lengthening of patent monopolies.</p>	<p>Licensors may be willing to license a medicine for use with respect to a specified disease, typically a global health related infectious disease, but unwilling to license that same medicine for other indications/uses where it desires to exercise present or future control.</p> <p>Likewise, licensors may intend to continue investigating new uses for the medicines and may in the future seek regulatory approval for the same. Some licensors would be unwilling to give unfettered territorial access to a potential new use therapy where they might otherwise have profit-driven commercial prospects. The possibility of broader uses might also compromise the territorial reach of a license.</p> <p>Licensors may have a general "ideological" desire to limit licenses to specific diseases or conditions making them hesitant to grant unrestricted, open use licenses.</p> <p>There might be some overprescribing of medicines for unapproved conditions or the expanded use of a medicine might produce negative information on the medicines that would undermine its commercial prospect and even potentially tarnish the licensor's brand identity.</p> <p>Allowing royalty payments on expanded uses might produce unanticipated windfalls for licensors not anticipated at the time of licensing.</p>

ii. Pediatric use or pediatric formulations only

Some originator licensors have been willing to grant VLs for pediatric use, but have either wanted to treat adult use differently, e.g., ViiV for ABC and DTG,<sup>104</sup> or have wanted to avoid

104 ViiV licenses ABC for mono- and co-formulation for children, although it allows

adult licensing altogether, e.g., Merck Sharp & Dohme (MSD) for Raltegravir.<sup>105</sup> Certain licensors enforce a pediatric restriction by an age restriction,<sup>106</sup> whereas another licenses specific pediatric formulations.<sup>107</sup> Because pediatric AIDS medicines comprise such a small and non-remunerative market for pharmaceutical innovators,<sup>108</sup> companies granting pediatric licenses apparently do so mainly for reputational benefits without any real risk to corporate profits. Indeed, some of them actually gain potential access to innovative pediatric formulations because of grantback rights.<sup>109</sup> Of course, it is preferable if licenses grant field-of-use for all patients, adult and pediatric. However, if only pediatric coverage can be secured, it should be on a basis that allows both mono- and co-formulation<sup>110</sup> and access to all appropriate pediatric age-group formulations, including future formulations such as the 4/1 sprinkle formulations being developed by Cipla in consultation with DNDi.<sup>111</sup>

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only co-formulation for adults. See Medicines Patent Pool Foundation License Agreement, MEDS. PATENT POOL § 1.12, <https://medicinespatentpool.org/uploads/2013/02/ABC-Form-of-Sublicense.pdf> (last visited Jun. 12, 2018); ViiV-MPP Adult Sublicense Agreement Form, *supra* note 87, §§ 1.24–1.25. ViiV has a separate pediatric license for DTG. See Medicines Patent Pool Foundation License Agreement with ViiV Healthcare Co., MEDS. PATENT POOL, <https://medicinespatentpool.org/uploads/2017/07/ViiV-MPPF-Paediatric-Execution-Version-31-March-2104-clean.pdf> (last visited June 12, 2018) [hereinafter ViiV-MPP Pediatric [Sub] License].

105 MSD-MPP License Agreement, *supra* note 100.

106 See *id.* § 1.5 (pediatric patients under 12 years of age); ViiV-MPP Adult Sublicense Agreement Form, *supra* note 87, §§ 1.3, 1.10 (defining adult patients as over 18, resulting in pediatric patients being under 18).

107 AbbVie's pediatric license for Lopinavir/ritonavir (LPN/r) provides the best example of this restrictive approach where AbbVie licensed only the new LPN/r 40mg/10mg sprinkle formulation to the MPP, implicitly excluding 100/25 formulations appropriate for older children. Medicines Patent Pool Foundation License Agreement with AbbVie Inc., MEDS. PATENT POOL § 1.9, <https://medicinespatentpool.org/uploads/2017/07/MPP-AbbVie-Agreement-Final1.pdf> (last visited June 12, 2018) [hereinafter AbbVie-MPP Pediatric Sublicense] (defining licensed products).

108 Brenda Waning et al., *The Global Pediatric Antiretroviral Market: Analyses of Product Availability and Utilization Reveal Challenges for Development of Pediatric Formulations and HIV/AIDS Treatment in Children*, 10 BMC PEDIATRICS, no. 74, 2010, at 2, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2964660/pdf/1471-2431-10-74.pdf>.

109 AbbVie-MPP Pediatric Sublicense, *supra* note 107, § 5.

110 AbbVie's pediatric license does allow such co-formulation with "other active ingredients." *Id.* at §§ 5, 1.9.

111 DRUGS FOR NEGLECTED DISEASES INITIATIVE, TOWARDS ENDING THE NEGLECT OF PAEDIATRIC HIV? (2017), <https://www.dndi.org/wpcontent/>

*Recommended standard: Pediatric access licenses should allow all age-appropriate mono- and co-formulations.*

### iii. Research rights

Many countries have an explicit limited exception in their patent law allowing research on or with a patented technology in order to encourage ongoing innovations and improvements to patented inventions. Article 30 of the TRIPS Agreement allows for such limited exceptions, and a significant subset of countries allow for both commercial and non-commercial research use.<sup>112</sup> However, not all countries do so, including, in particular, the U.S., which has sharply curtailed the research exception even in academic settings.<sup>113</sup> VLs should encourage a virtuous cycle of follow-on innovation. For example, AbbVie's pediatric license with the MPP expressly defines the right to exploit patented products to include research and development with the possibility that new formulations might be developed and thereafter be subject to grantback rights to the licensor.<sup>114</sup> Nonetheless, even though granting such research rights is relatively routine in MPP and other licenses, it would be highly desirable for VLs field-of-use provisions to expressly permit commercial and non-commercial research on or with the licensed medicine.

*Recommended standard: Access licenses should allow commercial and non-commercial research.*

### f. Co-formulation rights

Although the right to co-formulate a licensed medicine with another medicine clinically approved for joint administration might be considered a field-of-use issue, it is important enough to discuss separately. The MPP has generally provided that its licenses grant freedom to develop clinically approved co-formulation<sup>115</sup> because of

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uploads/2017/12/DNDi\_Paediatric\_HIV\_December\_2017.pdf.

112 TRIPS Agreement, *supra* note 16. See WIPO, *Exceptions and Limitations to Patent Rights: Experimental Use and/or Scientific Research*, SCP/20/4 (Nov. 18, 2013), [http://www.wipo.int/edocs/mdocs/patent\\_policy/en/scp\\_20/scp\\_20\\_4.pdf](http://www.wipo.int/edocs/mdocs/patent_policy/en/scp_20/scp_20_4.pdf).

113 *Madey v. Duke University*, 307 F.3d 1351 (Fed. Cir. 2002).

114 See AbbVie-MPP Pediatric Sublicense, *supra* note 107, §§ 1.6, 5.

115 "The licences also provide the freedom to develop new treatments such as fixed-dose combinations – single pills composed of several medicines – and special formulations for children." See MEDS. PATENT POOL, IMPROVING ACCESS/PROMOTING INNOVATION 4 (2017), <https://medicinespatentpool>.

the advantages of rational and improved co-formulation in terms of production costs, procurement, supply, and prescription logistics and patient adherence.<sup>116</sup> AbbVie's adult Lopinavir/ritonavir (LPN/r) license is somewhat ambiguous whether it allows co-formulation with other ARVs besides each other, which is particularly problematic vis-à-vis ritonavir, which can be used as a booster with other protease inhibitors.<sup>117</sup>

It is important that licenses not allow any co-formulation whatsoever to be brought to market, but only co-formulations that are clinically approved and where bio-equivalence data shows equivalence between separately administered and co-formulated medicines.<sup>118</sup> There is a problem of unapproved fixed-dose combinations, especially in India, and such fixed-dose medicines can have undesirable health impacts.<sup>119</sup>

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org/uploads/2017/06/July-2017-update-Brochure-LOWRES.pdf.

- 116 Editorial, *Treatment Adherence: Can Fixed-Dose Combinations Help?*, 3 LANCET DIABETES & ENDOCRINOLOGY 91 (2015); see also Katy A. van Galen et al., *The Effect on Treatment Adherence of Administering Drugs as Fixed-Dose Combinations versus as Separate Pills: Systematic Review and Meta-Analysis*, AIDS RES. & TREATMENT (Sept. 4, 2014), <http://www.hindawi.com/journals/art/2014/967073/>; Simon Thorn et al., *Effect of a Fixed-Dose Combination Strategy on Adherence and Risk Factors in Patients With or at High Risk of CVG*, 310 JAMA 918 (2013); Vanessa Selak et al., *Effect of Fixed Dose Combination Treatment on Adherence and Risk Factor Control Among Patients at High Risk of Cardiovascular Disease: Randomized Controlled Trial in Primary Care*, 348 BMJ 1 (2014), <http://www.bmj.com/content/bmj/348/bmj.g3318.full.pdf>.
- 117 MPP Abbvie License Agreement for Africa Execution, MEDS. PATENT POOL § 1.7-1.8 (Dec. 17, 2005), <https://medicinespatentpool.org/uploads/2017/07/MPP-AbbVie-License-Agreement-for-Africa-execution-copy.pdf> [hereinafter AbbVie-MPP Adult License] (defining licensed compounds as “the antiretroviral compounds known as lopinavir and ritonavir, individually or in combination, manufactured or sold for the sole purpose of use [in Licensed Product solely for Exploitation] in the Field in the Territory.” The grammar of this sentence would seem to suggest that only LPN and ritonavir may be used in combination, not combinations with other ARVs. The MPP interprets the provision to allow other co-formulation. *Lopinavir, Ritonavir (LPV/r)*, MEDS. PATENT POOL (Dec. 2015), <https://medicinespatentpool.org/licence-post/lopinavir-ritonavir-lpvr/>.
- 118 The ViiV-MPP Adult License requires (1) that the sub-licensees only sell combination products that have been recommended for HIV treatment by the WHO, (2) that the licensed products obtain WHO prequalification, be registered by a stringent regulatory authority, or receive temporary approval from the WHO Expert Review Panel, and (3) that the product be registered and receive all required permissions from countries where it is sold. ViiV-MPP Adult Sublicense Agreement Form, *supra* note 87, §§ 1.24, 4.2–4.3.
- 119 Valerie Evans & Allyson M. Pollock, *The Proliferation of Irrational Metformin*

*Recommended standard: Access licenses should allow co-formulation with other licensed and unlicensed medicines to create clinically approved fixed-dose combinations.*

## 2. Know-how, existing and future

Licensors are sometimes willing to offer current know-how to their generic licensees to help them develop and manufacture the medicines more quickly and with less upfront experimentation and investment. For example, Bristol-Myers Squibb (BMS) and Gilead licenses with the MPP have offered know-how, whereas AbbVie did not and ViiV has one license without technology transfer and another with a separate memorandum of understanding concerning collaboration and technology transfer for the purpose of developing pediatric formulations.<sup>120</sup> Licensors appear unwilling to offer related, future know-how improvements, presumably because the scope and value of that know-how is unknown. Because manufacturing know-how is secret, originator licensees frequently require confidentiality clauses prohibiting onward disclosure of licensed know-how to third

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*Fixed-Dose Combinations in India*, 3 LANCET DIABETES & ENDOCRINOLOGY 98 (2015).

- 120 “1.1 Definitions: Licensed Manufacturing Know-How means all technical information and know-how known to or Controlled by BMS or its Affiliates as of the Effective Date (including all manufacturing data, the percentages and specifications of ingredients, the manufacturing process, specifications, assays, quality control and testing procedures) that is identified by BMS as primarily and directly relating to, and reasonably necessary for, the making of the Licensed Products in the same manner that such Licensed Products have been made by BMS prior to the Effective Date.” BMS-MPP Agreement, *supra* note 88, §§ 1.1, 2.1 (addressing one-time technology transfer of manufacturing know-how). *But see* Gilead-MPP Restated License Agreement in India, *supra* note 90 (“‘Licensed Know-How’ shall mean (a) the know-how actually transferred to Licensee pursuant to the terms of Section 5.4 (either prior to or following the Effective Date) and (b) any other improvements or modifications to such transferred know-how (x) that are (i) specific to API and (ii) developed and controlled by Gilead during the term of this Agreement, and (y) specifically excluding any such improvements and modifications, methods and other know-how claimed in any patent or patent application.” (emphasis removed)). Section 5.4, in turn, references a one-time technology transfer of know-how only. *Cf.* AbbVie-MPP Adult License, *supra* note 117 (no know-how transfer); ViiV-MPP Adult Sublicense Agreement Form, *supra* note 87 (no know-how transfer); Memorandum of Understanding Between the Medicines Patent Pool Foundation and ViiV Healthcare Ltd. (Feb. 13, 2003), <https://medicinespatentpool.org/uploads/2017/06/MoU-ViiV-MPPF-13.02.2013.pdf>.



parties and also require commercially reasonable efforts to keep such information confidential.<sup>121</sup>

Nonetheless, trade-secret protected know-how that is not revealed in patent applications can be useful to generic licensees, though not all licensees will need it or want it. Many generic companies, especially those in India, are highly adept at reverse-engineering small chemical medicines and have specialized themselves in manufacturing efficiencies.<sup>122</sup> Frankly, they do not need manufacturing know-how. Some critics are concerned that originator know-how might actually be inferior or that its receipt will induce generic companies to become less inventive in terms of cost-saving efficiencies.<sup>123</sup> There might also be concern that know-how licenses may give rise to an independent ground for territorial restrictions and royalty payments even when valid patents do not otherwise bar generic manufacture and supply.<sup>124</sup> Thus, licenses should permit rejection of offered know-how.<sup>125</sup>

*Recommended standard: Public health VLS should grant know-how on an optional basis to licensees and know-how rights should expressly be disclaimed as creating an independent basis for territorial restrictions or entitlement to royalties.*

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121 BMS-MPP Agreement, *supra* note 88, § 11; *See, e.g.*, Gilead-MPP Second Amended and Restated License Agreement § 7.1 (June 10, 2015), <https://medicinespatentpool.org/uploads/2013/12/MPP-Gilead-Sciences-Amended-Licence.pdf>.

122 SUDIP CHAUDHURI, *THE WTO AND INDIA'S PHARMACEUTICALS INDUSTRY: PATENT PROTECTION, TRIPS, AND DEVELOPING COUNTRIES* 46–58 (2005).

123 REPORT ON A CONSULTATION BETWEEN CIVIL SOCIETY REPRESENTATIVES AND THE MEDICINE PATENT POOL/UNITAID, *supra* note 73.

124 BMS licenses give rights to sell outside the designated territory if no licensed patent rights or non-territorial patent rights are violated, but only if the generic licensee has not relied on manufacturing know-how. *See, e.g.*, BMS-MPP Agreement, *supra* note 88, § 2.7(c); BMS-MPP HCV License and Technology Transfer Agreement § 2.8(c), MEDS. PATENT POOL, <https://medicinespatentpool.org/uploads/2015/11/MPP-HCV-License-Agreement-BMS-FINAL-Web-00000002.pdf> [hereinafter BMS-MPP HCV License].

125 *See, e.g.*, BMS-MPP Agreement, *supra* note 88, § 4 (allowing for rejection of offered know-how).



Advantages of licensing know-how	Disadvantages of licensing know-how
<p>Licensed access to know-how can speed up product development, expedite registration, and facilitate manufacturing efficiencies that can ensure quality and reduce price.</p> <p>Access to future know-how might be equally or more important if the originator comes up with a major improvement.</p> <p>Option provisions allow the generic licensee to decide independently whether it wants to have access to originator know-how.</p> <p>Know-how licenses can be structured to prevent them from becoming an independent basis for territorial restrictions or royalty payments.</p>	<p>Many experienced generic companies do not need originator know-how and they should not be required to take it.</p> <p>Access to know-how presents some indeterminate risk that generic companies might become less involved with incremental innovations to improve manufacturing efficiency.</p> <p>Overly restrictive confidentiality clauses could permit license termination, and accepting know-how could lead to disputes about whether the licensee's comparable know-how was developed prior to the license or not.</p> <p>In some cases, originators have required know-how licensees to have delayed access to termination rights, binding generic licensees to the originator's license for an undesirable period of time.</p> <p>Know-how licenses could be (and are being) interpreted as an additional ground for imposing territorial restrictions, even in countries without patents, and for collecting royalties, conceivably beyond any relevant period of patent exclusivity.</p>

### 3. *Early working, data, and registration-related rights*

Gaining access to patent rights provides little real benefit unless licensees simultaneously are permitted to an early working of the patent for the purpose of seeking registration of the generic equivalent in licensed territories before patent expiration,<sup>126</sup> and unless licensees can overcome any registration-related rights that

<sup>126</sup> Countries that have early working or Bolar provisions might typically allow such activity anyway, but not all early working rules are ideal in terms of permitting export for the purpose of registration elsewhere. It is preferable to have a license provision that removes all doubt. *See, e.g.,* AbbVie-MPP Pediatric Sublicense, *supra* note 107, §§ 1.4–1.5 (defining “exploit or exploitation” and “development”).

might otherwise bar or delay registration in licensed territories, i.e., data exclusivity rights and patent-registration linkage bars where they exist.<sup>127</sup> Licensees may, in addition, require access to originator data that it used in its drug application dossier. MPP licenses directly address these barriers in licensed territories and provide access to needed registration-related data<sup>128</sup> and for waivers of registration-related exclusivity thereby allowing reference and reliance rights on data previously submitted to drug regulatory authorities by originators for the purpose of registering the licensed generic equivalent.<sup>129</sup> It should be noted that some MPP licenses allow for waivers only in licensed territories, e.g., AbbVie, whereas others allow waivers even in countries where sales are otherwise “in accordance with the terms of the Sublicense,” e.g., ViiV.<sup>130</sup> Because the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR) program requires approval or pre-approval of medicines purchased with its funds to be approved by the U.S. Food and Drug Administration (FDA), at least one licensee agrees to cooperate fully to assist licensees in receiving such approvals though issuance of selective waiver letters.<sup>131</sup>

*Recommended standard: Access licenses should provide access to needed licensors registration-related data and explicit waivers to data exclusivity and*

127 Data exclusivity prevents reliance on data submitted by originators to drug regulatory authorities, reliance on that data, or the fact of registration itself to provide comparators for required equivalence studies for follow-on generic applicants. Patent/registration linkage typically requires drug regulatory authorities to deny registration applications for generic medicines where a block patent is claimed or provide for notice to originators and delays in the registration process. Data exclusivity and patent-registration linkage are TRIPS-plus, but such provisions are present in some national legislation and the U.S. consistently seeks to incorporate such requirement in its trade negotiations. See Baker, *supra* note 29, at 308–13, 330, 342.

128 See, e.g., BMS-MPP Agreement, *supra* note 88, § 4.1 (undertaking to provide information necessary for registration).

129 See, e.g., AbbVie-MPP Pediatric Sublicense, *supra* note 107, § 2.4; BMS-MPP Sublicense and Technology Transfer Agreement, MEDS. PATENT POOL § 4.1 (a) (Oct. 2017), <https://medicinespatentpool.org/uploads/2017/07/Amended-and-Restated-Sublicense-Agreement-October-2017.pdf> [hereinafter BMS-MPP Sublicense Agreement]; Gilead-MPP Restated License Agreement in India, *supra* note 90, § 6.3; ViiV-MPP Adult Sublicense Agreement Form, *supra* note 87, § 5.8.

130 AbbVie-MPP Pediatric Sublicense, *supra* note 107, § 2.4; ViiV-MPP Adult Sublicense Agreement Form, *supra* note 87, § 5.8.

131 ViiV-MPP Adult Sublicense Agreement Form, *supra* note 87, § 4A.

*patent-registration linkage in all territories included in the license (actual/implied), and should expressly allow early working for purpose of registration or tentative registration in any licensed territory or otherwise permitted country of use.*

### **B. Patent Disclosure**

A major problem confronting potential generic entrants and procurers is determining the patent landscape on particular medicines. Although patents theoretically require publication, determining patent status of medicines and all relevant patents claimed in multiple jurisdictions can be extraordinarily difficult in part because of the absence of reference to the international non-proprietary name in patent applications.<sup>132</sup> Although patent disclosures may be included in bilateral commercial licenses, those licenses are not publicly accessible. Thus, it is an enormous advantage that the MPP has succeeded in requiring originators to disclose patents that are pending or granted in licensed territories. Indeed, in at least two instances, the MPP has succeeded in convincing licensors to disclose their global patent landscape,<sup>133</sup> and in another case granted patents

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132 There are growing advocacy efforts trying to amend patent laws to require originators to disclose international nonproprietary names on all pharmaceutical related patent applications, but those efforts have not received wide acceptance yet. WIPO has conducted a study on this issue discussing its benefits and feasibility. Standing Comm. on the Law of Patents, *Feasibility Study on the Disclosure of International Nonproprietary Names (INN) in Patent Applications and/or Patents*, WIPO Doc. SCP/21/9 (Sept. 23, 2014), [http://www.wipo.int/edocs/mdocs/scp/en/scp\\_21/scp\\_21\\_9.pdf](http://www.wipo.int/edocs/mdocs/scp/en/scp_21/scp_21_9.pdf); see also K. M. GOPAKUMAR & NIRMALYA SYAM, *A STUDY ON THE USE OF NONPROPRIETARY NAMES IN INDIA* (WHO 2007), <http://www.who.int/medicines/services/inn/InternationalNonproprietaryNameinindia.pdf>. A proposal to this effect in India has not yet been successful. See V. Lakshmikumaran, *India: Pharmaceutical Patent Guidelines Welcome*, *MANAGING INTELL. PROP.* (Dec. 11, 2014), <http://www.managingip.com/Article/3409546/India-Pharmaceutical-patent-guidelines-welcome.html>.

133 See, e.g., AbbVie-MPP Pediatric Sublicense, *supra* note 107, at Exhibit B; BMS-MPP Agreement, *supra* note 88, at Schedule C. This disclosure is voluntary and, as of the time of licensing and the completeness of the disclosures, has not been independently verified. The disclosure of patents by Gilead in its bilateral voluntary licensing agreement covering sobosbuvir and ledipasvir is suspected of being incomplete, particularly as it lists pending Patent Cooperation Treaty applications without further identifying countries selected in such applications. *HCV Licensing Agreement*, GILEAD SCI. 26–28, [https://www.gilead.com/~media/files/pdfs/other/2014\\_original\\_hcv\\_licensing\\_agreement.pdf?la=en](https://www.gilead.com/~media/files/pdfs/other/2014_original_hcv_licensing_agreement.pdf?la=en) (last visited June 19, 2018) [hereinafter *Gilead HCV License Agreement*].

in non-licensed-territory LMICs.<sup>134</sup> This added information is quite helpful to advocates, countries, and generic producers weighing options to pursue generic competition in non-licensed territories, whether by permitted extra-territorial sales or via compulsory or government-use licenses.

*Recommended standard: Public health VLs should require licensors to disclose their patent landscape in licensed territories, but also in non-licensed territories, especially where licenses allow sale when there are no blocking patents in the country of manufacture and sale.*

### C. Licensee Requirements and Restrictions

#### 1. Quality-only API sourcing restrictions vs. other limitations/restrictions on APIs including approved suppliers and countries-of-origin

Companies may or may not choose to address the licensees' rights with respect to sourcing an API. Generally, it is far preferable that licensors allow API production anywhere in the world for use in the manufacture of final products to be supplied to permitted markets in the licensed territory,<sup>135</sup> that they collect royalties on the basis of final formulation sales rather than API sales,<sup>136</sup> and that they address API quality-related issues. Gilead, on the other hand, has insisted that APIs can only be sourced from MPP-sublicensed API producers or other approved, Gilead-controlled sources of API.<sup>137</sup> These API supplier restrictions retard the development of competitive sources of API supply by limiting market opportunities for unapproved suppliers. At the same time, these restrictions can lead to higher cost APIs from approved suppliers who are more tightly controlled by the licensor.

Similarly, Gilead has restricted sourcing to API producers in certain countries. Originally, this pertained only to India, but now extends to China and South Africa as well.<sup>138</sup> These country-

134 ViiV-MPP Adult Sublicense Agreement Form, *supra* note 87, at Appendix D.

135 See, e.g., *id.* §§ 2.1(a), 2.2(b).

136 For example, BMS collects royalties only on sales of Licensed Products, not on the basis of the Licensed Compound, and similarly ViiV collect royalties only with respect to formulation products. BMS-MPP Agreement, *supra* note 88, § 3; ViiV-MPP Adult Sublicense Agreement Form, *supra* note 87, § 3.1.

137 Gilead-MPP Restated License Agreement in India, *supra* note 90, § 3.1.

138 *Inside Views*, *supra* note 72 (discussing original license and its term limiting manufacture to India). Cf. Gilead-MPP Restated License Agreement in India,

of-origin API restrictions are based on the API being subject to some degree of patent protection, e.g., a filed-patent, a granted patent, or an appealed patent denial, in the approved country of API production. In addition, these country-of-origin API restrictions are used by Gilead to justify strict territorial restrictions that do not allow sales outside of the licensed territories except in the instance where a compulsory license is granted<sup>139</sup> and to demand royalty-payments throughout the licensed territory on the sale of final products even where API patents and final product patents are not in force in particular countries of sale, import, and use.<sup>140</sup> Of course, such restrictions also negatively impact efforts to strengthen local or regional pharmaceutical manufacturing capacity. Restrictions on the sourcing of API can also run the risk of creating API shortages and bottlenecks, and thus shortages of final formulations negatively impacting ongoing and scaled-up treatment.

Finally, where available, it would be preferable for access licenses to require WHO prequalification with respect to authorized API suppliers,<sup>141</sup> or alternatively to require Good Manufacturing Practice-assured API supply.

*Recommended standard: Public health licenses with respect to APIs should permit no or only quality-related restrictions on API sourcing and should not place anti-competitive restrictions on API suppliers or country of API manufacture.*

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*supra* note 90, § 2.1.

139 Gilead-MPP Restated License Agreement in India, *supra* note 90, § 10.3(d).

140 *Id.* § 4.1 (specifying that royalties are due on net sales of product in the territory during the royalty term).

141 *Active Pharmaceutical Ingredients*, WHO, <https://extranet.who.int/prequal/content/active-pharmaceutical-ingredients> (last visited June 19, 2018).

Advantages of allowing only quality-related restrictions on sourcing of APIs	Disadvantages of allowing only quality-related restrictions on sourcing of APIs
<p>No limits on API sourcing results in a truly globally competitive market for the key ingredient to medicines; robust global competition in turn leads eventually to lower prices and helps to ensure market sustainability.</p> <p>Allowing global sourcing encourages development of domestic capacity both to produce API and to formulate final pharmaceutical products with imported API. This helps to avoid the risk of localized or global shortages.</p> <p>Although some degree of subsidization might be necessary in early stages as the local industry develops capacity, expands its market, and reaches efficient economies-of-scale, the mid- and long-term goal is a competitive domestic industry that can potentially export regionally or internationally as well as service national demand.</p> <p>Even so, limitations relating to quality can help incentivize API producers to produce according to Good Manufacturing Practice standards and thereby reduce the risk of substandard or poor quality medicines.</p>	<p>Insisting on unrestricted or quality-only restrictions on API can deter some innovators from licensing their APIs to licensees bilaterally or to the MPP.</p> <p>Originators/patent-holders want some basis for imposing geographical limitations on licensed sales because they want to preserve rich and pharmerging markets for themselves. Controlling the API country source of supply can provide the basis for such contractual control. Taking the control away risks reaching a licensing agreement.</p>

**2. Licensee restrictions: countries of final product manufacture, control on number/selection of licensees, and affordability**

As with APIs, access licenses can optimally permit manufacture anywhere in the world, including non-licensed territories,<sup>142</sup> or they can sub-optimally seek to limit places of final formulation manufacture in order to more tightly control territorial restrictions and justify collection of royalties. Gilead imposes tight controls on the country of final-product production as it does for APIs,

<sup>142</sup> See, e.g., ViiV-MPP Adult Sublicense Agreement Form, *supra* note 87, §§ 2.1(b), 2.2(a). AbbVie, BMS, and MSD licenses also allow production anywhere in the world.

limiting production to India, China, and South Africa where there are pending, granted, or under-appeal patents.<sup>143</sup> This restriction in turn serves as a basis for restricting territories of distribution and use and collecting royalties even in countries without any domestic blocking patents. This country-of-origin limitation undesirably restricts the number of potential licensees, and it also interferes with the development of pharmaceutical capacity in other LMICs.

Similarly, VLs can be granted only to select, favored licensees, on an open-license basis, or on a forecasted, market-need basis to licensees who can meet stated criteria in terms of quality and willingness to serve licensed territories. Historically, bilateral licenses have been granted to single entities, e.g., GlaxoSmithKline's early licenses with Aspen Pharmacare,<sup>144</sup> or to a small number of preferred licensees, e.g., Gilead's early ARV license.<sup>145</sup> Licenses to single licensees will not ordinarily result in significant cost savings for purchasers unless those licensees are subject to equitable pricing provisions or other competitive pressures. Even a few licensees might not be enough to stimulate competition unless there are non-licensees who have also entered the market or unless global pricing agreements have been reached via the Clinton Health Access Initiative (CHAI) or otherwise.<sup>146</sup> The ideal situation is a

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143 Gilead-MPP Restated License Agreement in India, *supra* note 90, § 2.2; First Amendment to [Amended and Restated] License Agreement, GILEAD SCI. § 2.2, [https://medicinespatentpool.org/uploads/2017/10/MPP-2nd-AR-License-Amendment-1-Appendix-8-C\\_06.11.2017.pdf](https://medicinespatentpool.org/uploads/2017/10/MPP-2nd-AR-License-Amendment-1-Appendix-8-C_06.11.2017.pdf) (last visited June 19, 2018); First Amendment to License Agreement, GILEAD SCI. § 2.2, [https://medicinespatentpool.org/uploads/2017/10/MPP-2nd-AR-License-Amendment-1-Appendix-8-D\\_6.11.2017.pdf](https://medicinespatentpool.org/uploads/2017/10/MPP-2nd-AR-License-Amendment-1-Appendix-8-D_6.11.2017.pdf) (last visited June 19, 2018); see *MedsPal Database on Relevant Patents in China*, MEDS. PATENT POOL, [http://www.medspal.org/?country\\_name=China](http://www.medspal.org/?country_name=China) (last visited June 19, 2018).

144 Reuters, *GlaxoSmithKline Gives AIDS Drug Rights to Generic Maker*, N.Y. TIMES (Oct. 9, 2001), <http://www.nytimes.com/2001/10/09/business/glaxosmithkline-gives-aids-drug-rights-to-generic-maker.html>.

145 Keith Alcorn, *Gilead Will License Tenofovir to Indian Companies; Merck to Take Atripla to Africa*, NAM AIDS MAP (July 26, 2006), <http://www.aidsmap.com/Gilead-will-license-tenofovir-to-Indian-companies-Merck-to-take-iAtripla-to-Africa/page/1424405/>.

146 CHAI has historically worked to establish ceiling, and now reference prices, on key ARVs. See *Access Programs*, CLINTON HEALTH ACCESS INITIATIVE, <https://clintonhealthaccess.org/program/access-programs/> (last visited Jan. 24, 2018). For a description of the current state of the ARV market, including CHAI's work on the same, see Clinton Health Access Initiative, *The State of the Antiretroviral Drug Market in Low- and Middle-Income Countries 2016–2021*, ANTIRETROVIRAL MKT. REP., Sept. 2017, at 1, <https://clintonhealthaccess.org>.



large, aggregated market with multiple licensees who can compete sustainably at efficient economies-of-scale. This scenario of multiple generic suppliers is most likely to result in both affordable pricing and security of supply.

To achieve a truly competitive market, some advocates recommend open licenses—licenses that any qualified entity can sign onto and thereafter manufacture and distribute licensed medicines pursuant to the licenses' terms.<sup>147</sup> Alternatively, licensors for licensing intermediaries like the MPP can try to calibrate the number of licensees to the anticipated market and screen for quality. The MPP issues Expressions of Interest by which generics can apply for sublicenses when a new MPP in-license is received.<sup>148</sup> The MPP determines the number of licenses to grant based on WHO/MPP product-need forecasts.<sup>149</sup> Not only does the MPP impose stringent quality standards that the prospective licensee must agree to in advance, it seeks information on anticipated product development expenditures, registration plans, sourcing of API, and many other topics.<sup>150</sup> In essence, the MPP engages with prospective licensees to determine whether they can act as reliable suppliers, whether they can service a significant number of licensed countries, and whether they are committed to affordable pricing, though it does not directly seek to control costs.

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org/content/uploads/2017/09/2017-ARV-Market-Report\_Final-2.pdf.

147 See James Love & Tim Hubbard, *Prizes for Innovation of New Medicines and Vaccines*, 18 ANNALS HEALTH L. 155, 174–77 (2009).

148 *Expressions of Interest*, MEDS. PATENT POOL, <https://medicinespatentpool.org/what-we-do/expression-of-interest/> (last visited June 26, 2018).

149 *Id.* See *Forecasting*, MEDS. PATENT POOL, <https://medicinespatentpool.org/what-we-do/forecasting/> (last visited June 26, 2018).

150 MPP requests interested generic licensees

to provide details of your capacity, capabilities and record for manufacturing quality-assured medicines, your R&D, regulatory compliance and financials. You should also provide specific plans for the products you wish to license. These should cover development, manufacturing, regulatory plan, distribution and predicted investments. Among other criteria, we will consider your organisation's state of readiness with needed formulations, including fixed-dose combinations and paediatric formulations. . . . Criteria such as viability of development plans (especially in case of projects requiring specific capital expenditure or investments), quality and past performance (especially in case of serious breaches of voluntary licence agreements) may result in us rejecting an application.

*Expressions of Interest*, *supra* note 148.

Two additional variations on quasi-open licenses are (1) circumstances where the right holder maintains some contractual power to approve licensees otherwise acceptable to an intermediary like the MPP,<sup>151</sup> and (2) circumstances where the right holder enters into separate bilateral licensing agreements with its favored generic partners for particular territories even as it grants more open licenses to other territories. Gilead followed this second option at the time of its original ARV license with the MPP when it entered into four separate licenses for generics for sales in select markets.<sup>152</sup> This strategy was strongly critiqued.<sup>153</sup>

Licensors may also attempt to ensure affordable pricing in their licensing agreements.<sup>154</sup> These requirements could be even more pro-access if they restricted mark-ups or otherwise controlled prices.

*Recommended standard: Public health VLs should ordinarily be open to all qualified producers, without territorial restrictions on the place of production, and should seek to assure affordable access.*

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151 See, e.g., AbbVie-MPP Pediatric Sublicense, *supra* note 107, § 3.4; BMS-MPP Agreement, *supra* note 88, § 2.3(b)(viii).

152 “In July 2011, on the same day the Gilead-MPP agreement was made public, Gilead also announced it had also signed separate (i.e. not within the MPP) semi-exclusive licensing agreements with four ‘preferred Indian generic partners.’ These licences include semi-exclusive rights for five years to market three drugs - elvitegravir (EVG), cobicistat (COBI), and a combination pill termed ‘the Quad’ (TDF/FTC/COBI/EVG) - to a list of countries, including nine countries that are excluded from the terms of the licences signed on the same day by Gilead with the MPP . . . the terms of these separate licences set higher royalty rates and include no termination clause, and the licences carve up the nine countries between the suppliers, so that each of the four companies has semi exclusivity in particular territories.” *MSF Review of the July 2011 Gilead Licenses to the Medicines Patent Pool*, *supra* note 72, at 4. Footnote nine in *MSF Review of the July 2011 Gilead Licenses to the Medicines Patent Pool*, *supra* note 72, mentions that “Matrix has semi exclusivity in Sri Lanka and Thailand; Ranbaxy Laboratories Ltd and Hetero Drugs Ltd have semi-exclusivity [sic] in Botswana and Namibia; and Strides Aroclab LTD has semi-exclusivity in El Salvador, Ecuador, Indonesia, Kazakhstan and Turkmenistan.” *Id.* at 4 n.9.

153 See, e.g., *id.* at 4.

154 See, e.g., BMS-MPP Agreement, *supra* note 88, § 5(c); BMS-MPP Sublicense Agreement, *supra* note 129, § 5(c) (requiring the MPP and the licensee to use all reasonable efforts to promote the affordable access to the licensed products in the licensed territory).

### 3. License restrictions: anti-diversion policies

VLs almost always have anti-diversion policies that attempt to restrict sales of licensed products outside the permissible direct and indirect territorial scope of the license or to third parties, including distributors, whom licensees reasonably suspect might divert the authorized medicine to unauthorized countries.<sup>155</sup> As a first line of defense against diversion, agreements require some degree of product differentiation to prevent brand confusion and to protect the trademark and trade dress of the originator.<sup>156</sup> Certainly, the product name, packaging, and labeling are changed,<sup>157</sup> and sometimes there may be differentiation in product size and/or shape and color as well.<sup>158</sup> However, extreme product differentiation has the risk of confusing patients about the substitutability of generic equivalents.<sup>159</sup> Nonetheless, at least one originator, ViiV, requests the right to examine and approve proposed product differentiation.<sup>160</sup> Although most anti-diversion policies address international diversion, if a license is granted for particular in-country sectors, e.g., the public sector only, the originator may also seek to prevent anti-diversion measures between supply chains in the subject country.<sup>161</sup>

However, agreements may also require strict monitoring of

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155 AbbVie-MPP Adult License, *supra* note 117, § 3.6; *See, e.g.*, BMS-MPP Agreement, *supra* note 88, §§ 2.7, 13.3(b)(i); Gilead-MPP Restated License Agreement in India, *supra* note 90, § 22 (amending § 7.2 of the underlying license agreement); MSD-MPP License Agreement, *supra* note 100, § 4; ViiV-MPP Adult Sublicense Agreement Form, *supra* note 87, § 8.

156 MPP licenses expressly disclaim any licensing of trademark. *See, e.g.*, AbbVie-MPP Adult License, *supra* note 117, § 2.2; BMS-MPP Agreement, *supra* note 88, § 2.4; Gilead-MPP Restated License Agreement in India, *supra* note 90, § 5.3(a); MSD-MPP License Agreement, *supra* note 100, § 2.2; ViiV-MPP Adult Sublicense Agreement Form, *supra* note 87, § 10.

157 *See, e.g.*, ViiV-MPP Adult Sublicense Agreement Form, *supra* note 87, § 8.2.

158 *See, e.g., id.* § 8.3 (allowing ViiV significant control over visual differentiation unless the differentiation affects stability); Gilead-MPP Restated License Agreement in India, *supra* note 90, § 5.3(a) (requiring a distinct color and shape). Although these issues about trade dress are not addressed in the ViiV and Gilead licenses, changes in size and shape might also affect bioavailability and bioequivalence. Baker, *Arthritic Flexibilities for Accessing Medicines*, *supra* note 3, at 650 (addressing concerns about possible impacts on trade dress changes on bioequivalence).

159 Jeremy Green & Aaron Kesselheim, *Why Do the Same Drugs Look Different? Pills, Trade Dress, and Public Health*, 365 *NEW ENG. J. MED.* 83 (2013).

160 ViiV-MPP Adult Sublicense Agreement Form, *supra* note 87, § 8.3 (allowing ViiV to inspect and approve appearance of trial batches).

161 *See, e.g., id.* § 8.1(d).

third party resellers within licensees' distribution and supply chain, including licensors' rights of approval of reseller agreements, licensor termination rights, and stringent reporting requirements.<sup>162</sup> License agreements may require generic licensees to impose anti-diversion terms on their own buyers and distributors and to terminate supply relationships for major, unremediated product diversions.<sup>163</sup> With newer technologies, including barcodes and radio chips, future licensors may become even more demanding, retracing medicines throughout the supply chain.

Gilead's anti-diversion clauses in its HCV VL and its related anti-diversion plans<sup>164</sup> were reported to be quite draconian. These clauses went so far as to demand stringent control of patient access by collecting information on addresses and citizenship and requiring the return of empty bottles before collection of the next month's supply.<sup>165</sup> Gilead has denied that it imposed any direct criteria that compromised patient confidentiality or the physician-patient relationship. However, concerns about the company's anti-diversion policies remain, including impacts on medical tourism, license terminations, and patients' rights, as well as other concerns.<sup>166</sup>

Critics of VLs, including MPP licenses, have expressed concerns that any anti-diversion policies negatively impact other

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162 Gilead-MPP Restated License Agreement in India, *supra* note 90, §§ 2.5, 4.3.

163 *Id.* § 2.5(f).

164 Gilead HCV License Agreement, *supra* note 133, § 6.1(a).

165 Brook K. Baker, *The Cynical Connectedness of Gilead's Hepatitis C Pricing and Anti-Diversion Policies*, THE BODY PRO: HIV/AIDS BLOG CENTRAL (Jan. 16, 2015), <http://www.thebodypro.com/content/75407/the-cynical-connectedness-of-gileads-hepatitis-c-p.html>; MÉDECINS SANS FRONTIÈRES, BARRIERS TO ACCESS AND SCALE-UP OF HEPATITIS C (HCV) TREATMENT: GILEAD'S ANTI-DIVERSION PROGRAM (2015), [http://www.msface.org/sites/default/files/HepC\\_Gilead\\_anti-diversion\\_FINAL\\_updated%20clean\\_0.pdf](http://www.msface.org/sites/default/files/HepC_Gilead_anti-diversion_FINAL_updated%20clean_0.pdf). For additional critical analysis of the Gilead HCV License, see Brook K. Baker, *Gilead's Proposed Hepatitis C Medicines License – How Badly Will it Miss the Target?*, HEALTH GAP: BLOG (Sept. 16, 2014), [https://www.healthgap.org/hep\\_c](https://www.healthgap.org/hep_c).

166 Overly stringent anti-diversion policies such as those adopted by Gilead licensees in its hepatitis C licenses can infringe on patients' rights to privacy, confidentiality, and treatment. Requirements to return empty bottles or travel distances can adversely impact adherence to treatment and impose high opportunity costs on patients. Vulnerable groups, particularly displaced persons, criminalized populations, and migrants are adversely affected by requirements of identity papers and proof of address. Medical tourism and the travelers exemption of medicines carried into a country for personal use can also be adversely affected. See sources cited *supra* note 165.

countries' right of parallel importation.<sup>167</sup> Under parallel importation rules authorized by the TRIPS Agreement,<sup>168</sup> if an authorized licensed product is sold more cheaply in another country, a country adopting international exhaustion, which allows parallel importation, can buy that product from the country of first sale and import it for permissible domestic use and consumption.<sup>169</sup> Anti-diversion clauses create a contractual limitation on this right and force distributors to disallow parallel export/import. Of course, the critics are correct that anti-diversion provisions, when coupled with territorial restrictions, undermine that parallel importation flexibility. On the other hand, it is difficult to see how an originator would ever grant an access license that was intended to service LMICs that was in fact a global license for countries adopting an international exhaustion regime. Frankly, from a commercial standpoint, the whole point of territorial restrictions is to save some potentially lucrative markets exclusively to the originator. Reducing the risk of diversion, especially to priority markets, may make companies more willing to expand the number of covered territories.

*Recommended standard: Although the ideal public health VLs would contain minimal anti-diversion clauses and diversion-related termination provisions, anti-diversion policies and product differentiation clauses should avoid creating patient confusion about the generic equivalents, should not adversely impact the traveler's exemption, and should not undermine patient rights and physician/prescriber/patient relationships.*

#### 4. License restrictions: quality

The issue of quality is often regulated in VLs. Even in bilateral licenses, the licensor frequently requires registration by stringent regulatory authorities because its reputation and brand can be negatively impacted by licensees' quality defects.<sup>170</sup> Bizarrely, Gilead's

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167 See, e.g., Shashikant & Gopakumar, *supra* note 73.

168 TRIPS Agreement, *supra* note 16, at art. 6.

169 There will ordinarily still be regulatory barriers to importation and use if the imported medicines have not been registered by the national drug regulatory authority.

170 See generally U.S. DEP'T OF HEALTH & HUMAN SERVS. FOOD & DRUG ADMIN., GUIDANCE FOR INDUSTRY: CONTRACT MANUFACTURING ARRANGEMENTS FOR DRUGS: QUALITY AGREEMENTS (2016), <https://www.fda.gov/downloads/drugs/guidances/ucm353925.pdf> (addressing contract manufacturing concerns that are analogous to voluntary licensing concerns).

HCV license originally only required that generics meet national regulatory requirements,<sup>171</sup> putting the supply of generic versions of its medicines at risk in terms of quality. A recent amendment to that license now requires meeting WHO prequalification, Indian, U.S. FDA, or European Medical Agency requirements as well as national requirements.<sup>172</sup> The quality standard imposed by the MPP–WHO prequalification, registration by a stringent regulatory authority, or approval by the WHO Expert Review Panel, which is actually required by the MPP’s funder Unitaid, requires adherence to a global standard of safety, efficacy, and quality.<sup>173</sup> As a result, all MPP licenses have similar, but not identical, quality and registration-related terms.<sup>174</sup> Some critics have expressed concern that the MPP’s requirement imposes an unreasonably strict standard for quality, especially since producers in Brazil and Thailand do not presently meet its standards, both of which are thought to produce medicines of assured quality.<sup>175</sup> Critics are also concerned that the pharmaceutical industry is pursuing a platinum standard of quality that is really designed as a barrier-to-entry rather than a meaningful safeguard on consistent, built-in-quality.<sup>176</sup>

Unfortunately, at this point, there is no independently

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171 Gilead HCV License Agreement, *supra* note 133, § 6.2(a). Gilead originally only permitted HCV licensees from India, presumably because the company trusts the ability of Indian generics manufacturers to meet international quality assurance standards. *Id.* §§ 2.1(a), 2.1(b).

172 Amended and Restated License Agreement, GILEAD SCI. IR. UC § 6.2(a), <http://www.gilead.com/-/media/files/pdfs/other/form%20ar%20hcv%20license%20agmt%20gild%2011202017.pdf?la=en>.

173 MPP-WHO Memorandum of Understanding, *supra* note 4, at art. 6.2.

174 See, e.g., AbbVie-MPP Adult License, *supra* note 117, § 3.3 (requiring WHO prequalification or meeting International Conference on Harmonisation standards); BMS-MPP Agreement, *supra* note 88, § 7.2 (Unitaid three alternative standard); Gilead-MPP Restated License Agreement in India, *supra* note 90, § 6.2(a) (WHO prequalification or European Medicines Agency or U.S. FDA standards); MSD-MPP License Agreement, *supra* note 100, § 2.1(a) (WHO prequalification or approval by a “stringent regulatory authority”); ViiV-MPP Adult Sublicense Agreement Form, *supra* note 87, § 4.2 (Unitaid three alternative standard).

175 *Review of the July 2011 Gilead Licenses to the Medicines Patent Pool*, *supra* note 72, at 11.

176 KM Gopakumar, *Big Pharma Fails in Bid to Influence WHO Regulatory Norms on Medical Products*, 286 TWN THIRD WORLD NETWORK, June 2014, at 18–22, <http://www.twn.my/title2/resurgence/2014/286/cover04.htm> (discussing the International Conference on Harmonisation of Technical Requirements for Registration of Pharmaceuticals for Human Use).



credible standard by which to judge whether countries that do not conform to WHO Good Manufacturing Practice standards are good enough. Until such a standard is set, it remains desirable that access licensees be required to meet international Good Manufacturing Practice standards and other relevant good practice standards addressing storage and distribution.

*Recommended standard: Prospective licensees should meet internationally approved good manufacturing practice standards and/or other agreed good practice standards addressing storage and distribution.*

#### **D. Territorial and Sector Coverage and Restrictions**

##### **1. Direct geographical inclusion and restrictions**

Clearly the most controversial provision in VLS is their territorial restrictions. Global health advocates have historically focused most of their attention on access for people living in LMICs. The original scope of bilateral VLS was fairly restricted and most often included, in the HIV context, only sub-Saharan Africa and low-income countries.<sup>177</sup> In defining territorial coverage, originators seemed to rely on standard factors that they also used in their tiered pricing decisions: gross national product (GNP) or gross national income (GNI) per capita and World Bank classification, disease burden, and occasionally health system capacity.<sup>178</sup> Although this licensed market was reasonably large, both geographically and by population, it was also mostly poor. This meant that robust generic competition might not have emerged had not major donor funding been provided through the Global Fund to Fight AIDS, Tuberculosis and Malaria<sup>179</sup> and the U.S. PEPFAR program.<sup>180</sup>

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177 See Press Release, Gilead Sciences, Inc., *supra* note 67. For a more general discussion of ARV bilateral licenses, see ESTEBAN BURRONE & KAREN TIMMERMANS, WORLD HEALTH ORG., UNITAID, PATENTS AND LICENSES ON ANTIRETROVIRALS (2014), [https://medicinespatentpool.org/uploads/2017/07/ARV-Snapshot\\_April2014Rev.pdf](https://medicinespatentpool.org/uploads/2017/07/ARV-Snapshot_April2014Rev.pdf).

178 See MÉDECINS SANS FRONTIÈRES, UNTANGLING THE WEB OF ANTIRETROVIRAL PRICE REDUCTIONS 58–63 (18th ed. 2016), [https://www.msfaaccess.org/sites/default/files/HIV\\_report\\_Untangling-the-web-18thed\\_ENG\\_2016.pdf](https://www.msfaaccess.org/sites/default/files/HIV_report_Untangling-the-web-18thed_ENG_2016.pdf).

179 See generally THE GLOBAL FUND, <https://www.theglobalfund.org/en/> (last visited June 24, 2018).

180 See generally U.S. PRESIDENT'S EMERGENCY PLAN FOR AIDS RELIEF, <https://www.pepfar.gov/> (last visited June 24, 2018).



More recent licenses, particularly but not exclusively those negotiated by the MPP, have expanded geographic coverage to include at least some MICs, especially lower-MICs. An aspirational goal of the MPP—achieved only three times thus far—is that all of its licenses would have an inclusive geographic scope covering all LMICs.<sup>181</sup> This goal is aspirational in part because of the growing recognition that nearly 75% of the poorest people in the world now reside in MICs and that percentage might grow in the future, particularly as countries “graduate” or transition to MIC status.<sup>182</sup> But, as seen in Table 1, *supra* section III, the territorial coverage of MPP licenses averages only 90% for adult licenses and 99% for pediatric licenses,<sup>183</sup> meaning that millions of people in excluded MICs are invariably left behind.

Some of these excluded MICs face grim prospects even as their economies grow. Because of discrete GNP or GNI per capita thresholds imposed by some donors, MICs stand to lose foreign aid as they climb the income ladder.<sup>184</sup> These same countries can face increasing pressures through trade agreements and other rich country demands to adopt TRIPS-plus IP protections that will increase pharmaceutical costs thereafter. Patent term extensions and supplementary protection certifications; eased standards of patentability that can result in an increasing number of evergreening secondary patents on new uses, formulations, dosages, and combinations; enhanced enforcement powers; and other provisions can all broaden, strengthen, and lengthen pharmaceutical monopoly

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181 At present, the only MPP licenses that cover all LMICs are the inoperable NIH-MPP Duranavir Licenses. Press Release, Medicines Patent Pool, US National Institutes of Health (NIH) First to Share Patents with Medicines Patent Pool as it Opens for Business (Sept. 30, 2010), <https://medicinespatentpool.org/mpp-media-post/us-national-institutes-of-health-nih-first-to-share-patents-with-medicines-patent-pool-as-it-opens-for-business/>. See also Pharco-MPP Ravidasvir License, *supra* note 95; University of Liverpool-MPP Nanotechnology License, *supra* note 95 (covering two high-income African countries as well).

182 See THE GLOBAL FUND, *EQUITABLE ACCESS INITIATIVE REPORT* 8, 13–14 (2016), [https://www.theglobalfund.org/media/1322/eai-equitableaccessinitiative\\_report\\_en.pdf](https://www.theglobalfund.org/media/1322/eai-equitableaccessinitiative_report_en.pdf).

183 See Table 1: Effective Direct and Indirect Coverage of MPP Licenses in Low- and Middle-Income Countries, *supra* section III.

184 THE GLOBAL FUND, *supra* note 182, at 7–8 (demonstrating that 75% of available external financing given by multilateral health financiers and development agencies have followed the World Bank’s lead in using income classification to inform key eligibility, allocation, and co-financing policies).

power, making medicines unaffordable both to patients and to government procurers.<sup>185</sup>

Even without the impact of TRIPS-plus trade agreements, income-tier geographical exclusions that deny access to more affordable generic equivalents in some lower- and the majority of upper-MICs can have dire public health impacts. This is especially true in instances when governments face excessive prices from originator companies that consider so-called pharmerging MICs as future profit centers. Indeed, much of the future growth in pharmaceutical sales globally will take place in large, fast-growing economies, most especially China, India, and Brazil.<sup>186</sup> Although some originators are beginning to adopt tiered pricing policies for MICs, their tiers are quite rigid and their bilaterally negotiated or unilaterally imposed prices are often disproportionately high.<sup>187</sup> These tiered pricing policies result in restricting patient access or forcing governments to cut other health services in order to purchase needed medicines. The underlying logic of profit maximization, which in many instances demands higher prices in countries with higher degrees of income inequality, tends to push tiered prices upward rather than downward.<sup>188</sup> And, in almost all instances where generic competition is allowed to emerge, generic prices are significantly lower than originator prices, even originator no-profit prices.<sup>189</sup>

In summary, MPP licenses reach a significant portion of people living with HIV but, in the case of BMS's Daclatasvir license, a much smaller percentage of people living with HCV.<sup>190</sup> Because of pressure from civil society and elsewhere, the geographical scope of

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185 See Brook K. Baker, *Trans-Pacific Partnership Provisions in Intellectual Property, Transparency, and Investment Chapters Threaten Access to Medicines in the US and Elsewhere*, 13 PLoS MED. 1 (2016), <http://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1001970>; Sean M. Flynn et al., *The U.S. Proposal for an Intellectual Property Chapter in the Trans-Pacific Partnership Agreement*, 28 AM. U. INT'L L. REV. 105, 149–97 (2012).

186 See sources cited *supra* note 42.

187 MÉDECINS SANS FRONTIÈRES, *supra* note 178, at 7–11, 55–63; As HIV Burden Overwhelmingly Shifts to 'Middle-Income' Countries, Access to Affordable Medicines is Under Threat, MÉDECINS SANS FRONTIÈRES (July 22, 2015), <http://www.msf.org/en/article/hiv-burden-overwhelmingly-shifts-'middle-income'-countries-access-affordable-medicines-under#A>.

188 Sean Flynn et al., *An Economic Justification for Open Access to Essential Medicine Patents in Developing Countries*, 37 J.L. MED. & ETHICS 184 (2009).

189 See MÉDECINS SANS FRONTIÈRES, *supra* note 178, at 55–57.

190 See *License Overview*, *supra* note 77.

licenses has been expanded by ViiV, Gilead, and BMS.<sup>191</sup>

The competing arguments for pragmatism versus principle and solidarity have presented a challenge to the access-to-medicines movement.

Pragmatic advantages of broad but incomplete coverage	Principle-based disadvantages of incomplete coverage
<p>VLs are negotiated either bilaterally on originators' terms or through intermediaries like the MPP. In both cases, originators hold most of the cards—there is little real negotiation power on the other side other than reputational benefit and the background threat of alternative access strategies such as patent law reform, oppositions, price controls, and compulsory licenses.</p> <p>An all-or-nothing approach will never be successful and will delay access for large numbers of people who might otherwise have expedited access to more affordable generics of assured quality, which is too high a price to pay even if the ultimate goal remains universal access.</p> <p>Alternative opposition and compulsory licensing strategies cannot achieve quick results or aggregate markets effectively since they require patent-by-patent, medicine-by-medicine, and country-by-country approaches.</p>	<p>When countries are excluded from licenses and when, as a consequence, a large number of people living with a disease are denied access to more affordable generics, it makes sense that access-to-medicines advocates in excluded countries and their global allies complain about the exclusions.</p> <p>Firm commitment, solidarity, and intense pressure by civil society and LMICs could result in near total geographical coverage.</p> <p>Other access strategies, most especially oppositions and compulsory licenses, force governments to act and take some of the power out of originators' hands.</p> <p>Acceptance of incomplete coverage satisfies some generic producers, some countries, and some advocates, undermining campaigns for law reform, opposition strategies, and compulsory licensing initiatives.</p>

## 2. *Contract provisions that expand geographical coverage indirectly*

In addition to broader direct territorial inclusion, better practices are emerging whereby the “indirect” inclusion of additional countries is expanding. At this point, it is important to reemphasize that originators can claim a legal basis for restricting territories and

191 *Dolutegravir – Adult (DTG)*, MEDS. PATENT POOL (Apr. 2014), <https://medicinespatentpool.org/licence-post/dolutegravir-adult-dtg/>; *Tenofovir Disoproxil Fumarate (TDF)*, MEDS. PATENT POOL (July 2011), <https://medicinespatentpool.org/licence-post/tenofovir-disoproxil-fumarate-tdf/>; *Atazanavir (ATV)*, MEDS. PATENT POOL (Dec. 2013), <https://medicinespatentpool.org/licence-post/atazanavir-atv/>.

limiting extra-territorial sales because of exclusive patent rights in countries of API supply, countries of final formulation production, and/or countries of sale and use. In other words, they can prevent sales in Lesotho, where no patent is in effect, if the country of production is South Africa where a patent claim is pending (creating provisional rights) or granted, or if there is a patent on the API granted or pending in China where the API is manufactured. Gilead is now infamous for strictly limiting extra-territorial coverage though its definition of licensed patents and its limiting API and formulation manufacturing to countries with granted or pending patent rights.<sup>192</sup> In addition to relying on putative patent rights and geographic restrictions on countries of manufacture, licensors can also seek to exercise extra-territorial control by means of the transfer of trade-secret protected know-how.<sup>193</sup> Accordingly, originators can exercise access hegemony and control of territorial rights in voluntary licensing agreements even when the vast majority of included and excluded LMICs have no patent in effect—originators can still delimit which countries are in and which are out.

However, certain licensing provisions can indirectly expand the number of covered countries. The first provision that might expand coverage is to limit IP-related claims in the license to “granted” patents as several MPP licensees have done. Admittedly, some countries where patents are pending might subsequently convert to covered patents, but nonetheless “controlled” territories can be reduced with this clause. Such a clause also enhances coherence with other strategies to expand access, and in particular pre-grant oppositions.

An even better provision is one that allows licensees to produce anywhere in the world and does not consider the patent status in the country of production as entailing rights to royalties or to export to extra-territorial countries where no granted blocking patent is in effect.<sup>194</sup> It is on this basis that the MPP license with ViiV

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192 Baker, *Inside Views*, *supra* note 72; Baker, *Gilead’s Proposed Hepatitis C License*, *supra* note 165; see sources cited *supra* note 73.

193 See BMS-MPP Agreement, *supra* note 88, § 2.7(c) (limiting extra-territorial sales to countries even without non-territorial patents if the licensee relies on licensed manufacturing know-how).

194 See, e.g., AbbVie-MPP Adult License, *supra* note 117, § 2.3; BMS-MPP Agreement, *supra* note 88, § 2.7(c) (but only when licensed manufacturing know-how has not been used); MSD-MPP License Agreement, *supra* note 100, § 4.1; ViiV-MPP Adult SubLicense Agreement Form, *supra* note 87, §§ 2.3, 2.5.

has such large, indirect territorial effect.<sup>195</sup> For example, the initial adult license covered a relatively small number of countries: 73.<sup>196</sup> The territorial scope of the MPP/ViiV adult license was subsequently expanded to cover all remaining lower MICs, including Armenia, Moldova, Morocco, and Ukraine where granted patents otherwise blocked access, benefiting 270,000 additional people living with HIV and providing direct generics in 92 countries.<sup>197</sup> Even though the defined territorial coverage was fairly limited, indirect coverage significantly expanded permission to supply to another 38 countries/territories.<sup>198</sup> Unfortunately, however, 14 MICs remain excluded from direct or indirect coverage in the adult license, because of patents granted or likely to be issued.<sup>199</sup> The sole remedy for these countries will be compulsory licenses as discussed, *infra* subsection IV.D.4..

### 3. Sector limitations, e.g., public sector

Another licensing provision that can expand geographical coverage, but with limitations, is a market segmentation clause such as that adopted in the ViiV-MPP adult license.<sup>200</sup> Here, the

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195 Brook Baker, *Beyond the Obvious – Direct and Indirect Territorial Coverage of MPP/ViiV Voluntary License for Dolutegravir*, INTELL. PROP. WATCH (May 24, 2017), <http://www.ip-watch.org/?s=Beyond+the+Obvious> [hereinafter *Beyond the Obvious*].

196 MAXIMILIANO SANTA CRUZ, REPORT OF THE MEDICINES PATENT POOL EXPERT ADVISORY GROUP ON THE PROPOSED LICENCE AGREEMENTS WITH ViiV HEALTHCARE FOR DOLUTEGRAVIR 2 (2017), <https://medicinespatentpool.org/uploads/2017/07/ViiV-DTG-EAG-Report.pdf>.

197 Press Release, Meds. Patent Pool, ViiV Healthcare, Medicines Patent Pool Extend Licence for Dolutegravir To All Lower Middle-Income Countries (Apr. 25, 2016), <https://medicinespatentpool.org/mpp-media-post/viiv-healthcare-medicines-patent-pool-extend-licence-for-dolutegravir-to-all-lower-middle-income-countries/>. Note: only public sector access was allowed in 10 royalty bearing countries. Baker, *Beyond the Obvious*, *supra* note 195.

198 *Id.* It is important to note that data exclusivity Rules could delay the right of generic sales in non-territory countries. See MÉDECINS SANS FRONTIÈRES, HIV & OPPORTUNISTIC INFECTION TREATMENT: SPOTLIGHT ON ACCESS GAPS 11–14 annex2 (2017), [https://msfaccess.org/sites/default/files/HIV\\_Brief\\_SpotlightOnAccessGaps\\_ENG\\_2017.pdf](https://msfaccess.org/sites/default/files/HIV_Brief_SpotlightOnAccessGaps_ENG_2017.pdf).

199 Baker, *Beyond the Obvious*, *supra* note 195 (referencing Algeria, Azerbaijan, Belarus, Brazil, Bulgaria, China, Colombia, Kazakhstan, Malaysia, Mexico, Mongolia, Romania, Russia, and Turkey).

200 The adult license is royalty-bearing in 10 countries where tiered royalty rates are applied as follows: Philippines, India, Vietnam, and Moldova (5%); Egypt, Indonesia, Morocco, Armenia and Ukraine (7.5%); Turkmenistan (10%). It is important to note that in all of these royalty-bearing markets authorized sales are permitted only pursuant to a procurement process within a Public Market,

licensor maintains control in the private sector, where negotiated or tiered-pricing can extract significant profits, while it grants licensees the right to sell in the public sector broadly defined. The public sector, which in some countries primarily serves poor people, often has significant resource constraints, and access to more affordable generics can generate significant cost savings. However, sector limitations are not without complications. First, the costs of supply chain security are real and the risks of product diversion and arbitrage are high—meaning that there is a risk that public sector generics will be diverted to in-country private market channels. If this happens, licensors retain power to end public sector licenses.<sup>201</sup> Second, many public sector pharmacies face significant stock-out problems such that poor patients must sometimes rely on private pharmacies to fulfill their medicines needs.<sup>202</sup> Although it would be theoretically possible for private pharmacies to hold originator and generic stocks and to fill public sector prescriptions with generics, the practicability and acceptability of such a solution is uncertain.

#### 4. *Special considerations concerning combination products*

One of the desired outcomes of MPP licenses and their provisions allowing licensed compounds to be co-formulated with other medicines in accordance with relevant treatment guidelines is to promote rational fixed-dose combination medicines that simplify procurement and supply and improve adherence to treatment.<sup>203</sup> However, when assessing the permissible licensed territory for

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and subject to prior approval by ViiV. However, Public Markets are broadly defined not just to include the public sector, but also NGOs, multilateral organizations, and major global health programs like PEPFAR and the Global Fund to Fight AIDS, Tuberculosis, and Malaria. See ViiV-MPP Adult SubLicense Agreement Form, *supra* note 87, §§ 1.35, 1.37, 2.4, 3.1.

201 *Id.* §§ 8.1(d), 13.5(a).

202 See, e.g., JOSEPH WALES ET AL., STOCKOUTS OF ESSENTIAL MEDICINES IN TANZANIA (2014), <https://twaweza.org/uploads/files/Stock-outs%20of%20essential%20medicines%20in%20Tanzania%20-%20ODI%20&%20TWA%20-%20final%20March2014.pdf>; Shankar Prinja et al., *Availability of Medicines in Public Sector Health Facilities of Two North Indian States*, BMC PHARMACOLOGY & TOXICOLOGY, Dec. 2015, at 1, [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4690305/pdf/40360\\_2015\\_Article\\_43.pdf](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4690305/pdf/40360_2015_Article_43.pdf).

203 Sripal Bangalore et al., *Fixed-Dose Combinations Improve Medication Compliance: A Meta-Analysis*, 120 AM. J. MED. 713 (2007); Feng Pan et al., *Impact of Fixed-Dose Combination Drugs on Adherence to Prescription Medications*, 23 J. INTERNAL MED. 611 (2008).



medicines co-formulated with compounds licensed from different licensors, it is important to remember that such fixed-dose combinations can only be sold in countries where direct and indirect coverage overlap for all relevant compounds. Thus, for example, efforts to market a new fixed-dose combination of TAF/3Tc/DTG might be limited to where there is overlap of permitted territories, remembering that Gilead's license, unlike ViiV's, does not permit indirect coverage outside the licensed territory where there are no blocking patents.

*Recommended standard: To the maximum extent possible, public health VLs should promote direct and indirect access to all LMICs through direct territorial inclusion, indirect inclusion through clauses that allow supply where there are no granted patents in the country of import or use, and even sector segmentation allowing access in the public sector broadly defined.*

#### *5. Expansion of territories by allowance of patent oppositions, invalidations, and pursuit/acceptance of compulsory licenses*

Licensors would like to treat VLs as patent settlements, meaning that they would like to restrict licensees' rights to oppose pending patent applications or to invalidate granted patents. They would also like to restrict licensees' rights to become compulsory or government-use licensees. Fortunately, competition policy in several countries restricts licensors' rights to prohibit non-exclusive licensees from opposing or seeking to revoke patents because such provisions are anti-competitive.<sup>204</sup> It is on this basis that Gilead revised its original bilateral ARV VLs to drop a clause preventing

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<sup>204</sup> See *Medimmune, Inc. v. Genentech, Inc.*, 549 U.S. 118, 137 (2007), (holding that a licensee is not required to break or terminate its license before seeking a declaratory judgment of patent invalidity). "Invalid patents impair competition, and, as a matter of patent policy, challenges to their validity are encouraged." U.S. DEPT OF JUSTICE & FED. TRADE COMM'N, ANTITRUST ENFORCEMENT AND INTELLECTUAL PROPERTY RIGHTS: PROMOTING INNOVATION AND COMPETITION 90 (2007), <https://www.ftc.gov/sites/default/files/documents/reports/antitrust-enforcement-and-intellectual-property-rights-promoting-innovation-and-competition-report.s.department-justice-and-federal-trade-commission/p040101promotinginnovationandcompetitionrpt0704.pdf>. The European Commission expressly outlaws non-opposition clauses in non-exclusive licenses. Commission Regulation No. 316/2014, art. 5.1(b), 2014 O.J. (L 93) 17, 22.



oppositions.<sup>205</sup>

The MPP has taken the position that its public health licenses should not restrict or otherwise limit licensees' ability to use TRIPS-compliant flexibility,<sup>206</sup> including flexibilities to oppose patent applications and to seek patent invalidation/revocation or to become a compulsory licensee. Although the right to oppose is not directly referenced in licenses, it is implied,<sup>207</sup> whereas the right to supply pursuant to a compulsory license is explicit.<sup>208</sup>

At least two countries have granted compulsory or government-use licenses to gain access to medicines licensed to the MPP. In 2012, Indonesia issued government-use licenses on seven ARVs, including one that is also active against hepatitis B<sup>209</sup> and

205 See sources cited *supra* note 63.

206 *Key Features of MPP Licenses*, MEDS. PATENT POOL, <https://medicinespatentpool.org/what-we-do/global-licence-overview/licensing-terms/> (last visited June 16, 2018) (key features include: compatible with the use of Trade-Related Aspects of Intellectual Property Rights Agreement flexibilities).

207 See BMS-MPP Agreement, *supra* note 88, § 2.7(c). In at least one instance, there are contractual consequences for filing for generic registration in the U.S. prior to patent expiration, namely the withdrawal of any relevant selective waiver letter allowing tentative regulatory approval that permits purchasing with PEPFAR funds. ViiV-MPP Adult SubLicense Agreement Form, *supra* note 87, § 4A.3(iii).

208 AbbVie-MPP Adult License, *supra* note 117, § 2.3; Gilead-MPP Restated License Agreement in India, *supra* note 90, § 10.3(d); MSD-MPP License Agreement, *supra* note 100, § 2.1(a); ViiV-MPP Adult SubLicense Agreement Form, *supra* note 87, § 4.2. Despite its clear intention to allow compulsory licenses, the MPP did not always adopt the most felicitous language to accomplish this goal. Critics had been particularly concerned with the 2011 Gilead ARV license, which is undesirably confusing about what a compulsory licensee must do when there is a license both in the country of production and in the country of importation/use. The use of “and/or” in Article 10.3(d) created ambiguity whether a potential compulsory licensee must be granted both in the country of manufacture and export, i.e., in India, and in the country of importation and consumption, if there were a blocking patent in that country as well. The best practice would be to make it clear that in such circumstances a compulsory license in the country of importation and consumption is sufficient and that the licensee would not have to seek or receive an additional compulsory license in the country of manufacture and export. This would help eliminate red tape and would be more consistent with the licensor's grant of manufacturing and distribution rights to the licensee in that country in the first instance. Article 10.3(d) has been subsequently modified in the disjunctive by amendment of “or” for “and/or.” Gilead-MPP Restated License Agreement in India, *supra* note 90.

209 See PUB. CITIZEN, INDONESIA LICENSES PATENTS FOR SEVEN HIV & HEPATITIS B MEDICINES, <https://www.citizen.org/sites/default/files/>

Ecuador issued a compulsory license on ABC and lamivudine.<sup>210</sup> More recently, in terms satisfying Gilead's HCV License, Malaysia issued a compulsory license on sofosbuvir, despite Gilead's belated decision to add Malaysia and three other countries to its licensed territory.<sup>211</sup> Some reports indicate that Malaysia was added to the VL because of the impending compulsory license.<sup>212</sup> Colombia has also declared a public interest in HCV medicines, a possible precursor to a compulsory license.<sup>213</sup>

*Recommended standard: Public health VLs should allow licensees to oppose pending patents on the licensed medicines, to seek revocation of granted patents on the licensed medicines, and to become compulsory licensees or to seek compulsory licenses with respect to the licensed medicines in other, any and all, territories. Such rights should be clearly and directly expressed, and it is highly desirable—in the case there are blocking patents both in the country of manufacture/export and importation/consumption—to require only a license in the importing country rather than both the importing and exporting country.*

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indonesia\_licenses\_patents\_for\_seven\_hiv.pdf (last visited June 25, 2018); Brook Baker, *Indonesian Compulsory Licenses Show Values of Pro-Access Trips-Flexibility Terms in Voluntary License*, INFOJUSTICE (Oct. 30, 2012), <http://infojustice.org/archives/27620>.

- 210 Ecuador Issues a Compulsory License on Abacavir/Lamivudine on 12 November 2012, KNOWLEDGE ECOLOGY INT'L (Nov. 15, 2012), <https://www.keionline.org/22041/>.
- 211 See Press Release, Malay. AIDS Council, Malaysian AIDS Council Welcomes Government Move to Issue Compulsory License on Lifesaving Hepatitis C Medicines (Sept. 11, 2017), <http://www.mac.org.my/v3/malaysian-aids-council-welcomes-government-move-to-issue-compulsory-license-on-lifesaving-hepatitis-c-medicines/> (discussing the issuance of the compulsory license); Ed Silverman, *Under Pressure, Gilead Expands Sovaldi Licensing Deal to Four Middle-Income Countries*, STAT: PHARMALOT (Aug. 24, 2017), <https://www.statnews.com/pharmalot/2017/08/24/gilead-sovaldi-malaysia-ukraine/>; see Amended and Restated License Agreement, *supra* note 172, app. a (adding Malaysia, Ukraine, Belarus, and Thailand).
- 212 Fifi Rahman, *Inside Views: Malaysia Inclusion in Gilead Voluntary Licence – A Product of Compulsory Licence Pressure*, INTELL. PROP. WATCH (Aug. 24, 2017), <http://www.ip-watch.org/2017/08/24/malaysia-inclusion-gilead-voluntary-licence-product-compulsory-licence-pressure/>.
- 213 Ed Silverman, *PhRMA is Angered by Colombia's Move to Cut Prices for Hepatitis C Drugs*, STAT: PHARMALOT (Jan. 16, 2018), <https://www.statnews.com/pharmalot/2018/01/16/colombia-hepatitis-oecd-license/>.

### E. Royalty Rates—Percentage and Tiered

VLs typically provide for a modest royalty payment,<sup>214</sup> usually calculated as a set percentage of the net sale price by the licensee, this is also true for MPP royalties, though royalties are uniformly waived for paediatric licenses.<sup>215</sup> Some licensors have charged higher royalty rates to favored licensees who are granted exclusive or near exclusive licenses in certain expanded territories, e.g., Gilead's 2011 bilateral ARV licenses.<sup>216</sup> Nonetheless, royalties are usually not a motivating factor for licensors to enter voluntary agreements, though they can provide some modest revenues over time. The MPP has experimented with more robust tiered royalties in its license with ViiV where higher royalty rates were paid on public sector licenses in certain MICs,<sup>217</sup> and with Pharco and the University of Liverpool.<sup>218</sup> Whether tiered royalties may be used creatively to open

214 For an extended discussion of royalty rates for compulsory licenses, see generally JAMES LOVE, REMUNERATION GUIDELINES FOR NON-VOLUNTARY USE OF A PATENT ON MEDICAL TECHNOLOGIES (Robert Weissman ed. 2005), <http://www.undp.org/content/dam/aplaws/publication/en/publications/hiv-aids/access-to-drugs-via-compulsory-licensing-guidelines--non-voluntary-patent-use/22.pdf>.

215 For MPP royalty terms, see AbbVie-MPP Adult License, *supra* note 117 (royalty free); see also AbbVie-MPP Pediatric Sublicense, *supra* note 107 (royalty free); BMS-MPP Agreement, *supra* note 88, § 3 (3% royalty for adult formulations, no royalty for pediatric formulations; royalties collected to be channeled back to community HIV organizations); BMS-MPP HCV License, *supra* note 124, § 2.1(a) (royalty free); *Products Licensed*, *supra* note 80 (links to Gilead-MPP ARV product pages and Key Features showing 5% royalty on BIC, COBI, EVG, and TAF final formulations; 3-5% royalty on TDF final formulations; no royalties on APIs, FTC, or pediatric formulations); MSD-MPP License Agreement, *supra* note 100, § 2.1; ViiV-MPP Adult SubLicense Agreement From, *supra* note 87, § 3 (adult license royalty free in 82 countries with a 5%-10% royalty in 10 MICs; no royalties for ABC or pediatric formulations); ViiV-MPP Pediatric [Sub] License, *supra* note 104, § 2.1-2.2 (no royalty); Pharco-MPP Ravidasvir License, *supra* note 95, § 4 (4%-12% royalty based on World Bank income status); University of Liverpool-MPP Nanotechnology License, *supra* note 95, § 7 (royalty free to a 1.75% royalty based income status and sector).

216 See MÉDECINS SANS FRONTIÈRES, *Review of the July 2011 Gilead Licenses to the Medicines Patent Pool*, *supra* note 72. See also *id.*, *supra* note 152.

217 ViiV-MPP Adult SubLicense Agreement Form, *supra* note 87, § 3 (adult license royalty free in 82 countries with a 5% royalty for the Philippines, India, Vietnam, and Moldova; 7.5% for Egypt, Indonesia, Morocco, Armenia, and Ukraine; and 10% for Kurkmenistan).

218 Pharco-MPP Ravidasvir License, *supra* note 95, § 4 (4% royalty in LICs, 7% in MICs, and 12% in high-income countries); University of Liverpool-MPP Nanotechnology License, *supra* note 95, § 7 (royalty free in Group 1 countries

up more MIC markets in other licenses remains to be seen, but at certain rates revenue streams could become significant. A common feature of MPP licenses is that they also provide guidance on how to apportion or split royalties where there are combination products.<sup>219</sup>

Although royalty charges do add to the final cost of medicines, and thereby have the potential to decrease the number of patients who can be treated for the same money, the competitive advantages and price savings of VLs that promote robust generic competition will usually more than offset these royalties. Moreover, royalties help place licenses on a more commercial basis and provide some measure of incentive to originators to enter into VLs in the first place, to expand territories, and to reward innovation and support future research and development (R&D). When originators' cost structure is significantly higher than generic licensees', royalty payments can offer clear commercial advantages over no-profit pricing. However, tiered-royalties, especially pharmerging upper-MICs, would have to be increased significantly in order to match profits earned on proprietary tiered pricing in MICs.<sup>220</sup>

One last issue relevant to royalties involves royalty payments on pending patents or on the basis of patents solely in the country of production even when there is no patent in the country of patient use. Gilead is now notorious for collecting royalties on the basis of pending patents and patents (or patent applications) only in the country of production. The best practice, as discussed previously, is to eschew royalty payments unless and until a patent has been granted in the country of patient use. A subsidiary problem that has not been addressed is what to do when a licensee has made royalty payments and the patent in question is later invalidated.<sup>221</sup> Licensing agreements could conceivably provide recoupment for royalties paid in such circumstances, but a review of license practice to date finds no example of this approach.

*Recommended standard: To promote maximum patient access and affordability,*

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and public sector of Group 2 countries, 1% royalty for private sales in Group 2 countries, 1.75% royalty in Group 3 countries, and no royalties for pediatric formulations).

219 See sources cited *supra* note 215.

220 For a discussion of a tiered-royalty method based on therapeutic effect and affordability that is more likely to produce significant revenue at least from MICs, see Love, *supra* note 214, at 85.

221 Note: a related issue arises when royalties have been paid based on a pending patent application but that application is ultimately rejected.

*royalty payments should remain modest for low-income and disease-burdened countries, but access VLs might reasonably include slightly higher or tiered royalty rates for lower- and upper-MICs; pediatric licenses should continue to have no royalties.*

#### **F. Grantback/Improvement Rights**

Licensees ordinarily have rights to experiment on or with the licensed medicines and therefore can incrementally innovate improvements and variations of product, including fixed-dose, pediatric, heat-stable, or delayed-release formulations.<sup>222</sup> In addition, licensees can innovate in the area of manufacturing know-how. Originator licensors are loathe to allow licensees to make improvements to licensed products without simultaneously gaining rights to those improvements for their own use. Otherwise, they might face the unenviable situation of ultimately having to compete with a superior product.<sup>223</sup> Thus, licensors ordinarily require that they be granted rights to all related product, process, and know-how improvements as part of their licensing deals.<sup>224</sup>

Competition policy in some countries frowns on grantback rights that discourage on-going innovation. Accordingly, exclusive grantbacks that deprive the licensee of any use of its own innovation or that provide assignment back to the licensor without compensation or other consideration are generally disfavored.<sup>225</sup> In

222 Depending on patent standards in particular countries, some of these improvements might be patent worthy.

223 Jay P. Choi, *A Dynamic Analysis of Licensing: The “Boomerang” Effect and Grant-Back Clauses*, 43 INT’L ECON. REV. 803 (2002); David J. Dykeman, *When Licensing Out Patents, Make Sure Improvements are Granted Back*, BOS. BUS. J. (Mar. 8, 2006, 5:18 PM), <http://www.bizjournals.com/boston/blog/mass-high-tech/2006/03/when-licensing-out-patents-make-sure.html>.

224 All such subject matter must ordinarily relate to the licensed technology and must not have pre-existed the license.

225 See, e.g., Commission Regulation 316/2014, 2014 O.J. (L 93) 17, 22 (discussing the application of Article 101(3) of the Treaty on the Functioning of the European Union to categories of technology transfer agreements, and Article 5.1(a), which declines to provide a safe-harbor for exclusive grantbacks and instead subjects them to anti-competitive assessment); Richard Schmalbeck, *The Validity of Grant-Back Clauses in Patent Licensing Agreements*, 42 U. CHI. L. REV. 733 (1975) (discussing U.S. law and recommending case-by-case competition analysis); U.S. DEPT. OF JUSTICE & FAIR TRADE COMM’N, ANTITRUST ENFORCEMENT AND INTELLECTUAL PROPERTY RIGHTS: PROMOTING INNOVATION AND COMPETITION 91–93 (2007); Susan Ning et al., *Risks of Grant-back Provisions in Licensing Agreements: A Warning to Patent-heavy Companies*, COMPETITION POLICY INT’L ANTITRUST CHRONICLE (2016)

addition, grantbacks might be limited to improvements that cannot be exercised without infringing the licensed IP, sometimes called “non-severable improvements,”<sup>226</sup> or they can also cover related but severable improvements that can be exercised without such infringement. Most commonly, both commercial and access licenses provide for some form of shared rights. Less frequently, licenses can provide purchase option rights to the licensor, or less often a full assignment, but only if it is accompanied by adequate compensation in terms of royalties or other payments.

The prospect for commercially valuable grantbacks can provide originators with additional financial motivation to enter into public health licensing agreements. Indian generics in particular compete on efficiencies both in chemical synthesis and in manufacturing process,<sup>227</sup> and these improvements can be commercially valuable to originators. However, it is access to improved products that is most attractive to originators, although the commercial impact of grantback rights from generic licensees has not been well documented.

On the other side of the table, licensees would have additional incentives to make commercially and therapeutically significant improvements if they were to receive compensation or royalties from licensors. Even low percentage royalties on high-price sales made in rich country markets could help licensees recoup the costs of innovation.<sup>228</sup> Such royalties would also reduce the competitive risk of having to recoup such costs in sales within licensed territories where LMIC procurers are not always eager to pay more, even for

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(analyzing Chinese law disfavoring exclusive and unreasonably compensated grantback provisions); cf. Law on Industrial Property (Law No. 9279/1996) (Braz.) (stipulating that “[a]n improvement introduced in a licensed patent shall belong to the party that makes the improvement, and the other party is entitled to a preferential right to the licensing thereof” thereby expressly authorizing grant-backs but without specifying terms for compensation).

226 The distinction between severable and non-severable improvements is well known in E.U. law. See, e.g., Maurits Dolmans & Anu Pilola, *The New Technology Transfer Block Exemption: A Welcome Reform, After All*, 27 *WORLD COMPETITION* 351, 359 (2004).

227 Isha Trivedi, *Fading Glory: Indian Pharma Industry in Uncharted Terrain*, *LIVEMINT* (June 23, 2017, 11:55 AM), <http://www.livemint.com/Industry/FsuFVKI1dNC30O4TyWeOGO/Fading-glory-Indian-pharma-industry-in-uncharted-terrain.html>. See generally Varun Mahajan et al., *Efficiency and Ranking of Indian Pharmaceutical Industry: Does Type of Ownership Matter?*, 7 *EURASIAN J. BUS. & ECON.* 29 (2014).

228 One MPP pediatric license with AbbVie provides an option for a 4% royalty on sales of new lopinavir/ritonavir pediatric formulations in the U.S. and E.U. AbbVie-MPP Pediatric Sublicense, *supra* note 107, § 5(a)(2).



improved medicines.

MPP licenses typically provide for non-exclusive grantback rights on all licensee improvements to the licensor without compensation,<sup>229</sup> though in at least one case, the pediatric license with AbbVie, the grantback license is royalty bearing.<sup>230</sup> With only one exception, the MPP does not retain any rights itself with respect to licensee improvements, e.g., rights that might be granted to other sublicensees upon payment of royalties or otherwise, though it has retained rights to negotiate sublicenses to other sublicensees.<sup>231</sup> Since part of the rationale of the MPP is to facilitate access to best-adapted and improved ARVs, it is of concern that its licensing agreements do not retain some form of grantback rights for other licensees. On the other hand, premature competition from other licensees that merely piggyback on the improvements disincentivizes licensees' incremental innovations. Since one of the main goals of the MPP is to encourage development of fixed-dose, pediatric, and improved

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229 See, e.g., *id.* (AbbVie has grantback rights on new formulations); BMS-MPP Agreement, *supra* note 88, § 9.1(b) (non-exclusive, perpetual, worldwide, royalty free grantback license to related inventions); BMS-MPP HCV License, *supra* note 124, § 8.1(b) (same); Gilead-MPP Restated License Agreement in India, *supra* note 90, § 2.4 (“non-exclusive, royalty-free, worldwide, sub-licensable license go all improvements, methods, modifications and other know-how relating to the licensed APIs or Products to both Gilead and the MPP”); MSD-MPP License Agreement, *supra* note 100, § 5.1 (non-exclusive, royalty-free, sub-licensable license to any Patented Improvement to Merck and the MPP, MPP may enter into good faith negotiation to sublicense); ViiV-MPP Adult SubLicense Agreement Form, *supra* note 87, § 9.2 (non-exclusive, perpetual, royalty-free, worldwide, license go all improvements, improvement patents and related know-how); ViiV-MPP Pediatric [Sub] License, *supra* note 104, § 8.2 (same); Pharco-MPP Ravidasvir License, *supra* note 95, § 3.5 (royalty-free, non-exclusive grantback to any Patented Improvements); University of Liverpool-MPP Nanotechnology License, *supra* note 95, § 4.1.4 (non-exclusive, perpetual, royalty-free, worldwide, license go all improvement).

230 The licensing agreement provides for a right of first refusal to purchase the paediatric formulation of LPN/r for sale in the U.S. and E.U. or an exclusive license for any patent or know-how for use in the U.S. and E.U. in exchange for a 4% royalty.

231 For licenses without grantbacks to the MPP, see AbbVie-MPP Pediatric Sublicense, *supra* note 107. The one exception is Gilead's license. Gilead-MPP Restated License Agreement in India, *supra* note 90, § 2.4. For licenses specifying future negotiations, see, e.g., BMS-MPP Agreement, *supra* note 88, § 9.1(b); BMS-MPP HCV License, *supra* note 124, § 8.1(b); MSD-MPP License Agreement, *supra* note 100, § 5.1; Pharco-MPP Ravidasvir License, *supra* note 95, § 3.5; ViiV-MPP Adult Sublicense Agreement Form, *supra* note 87, § 9.2; ViiV-MPP Pediatric [Sub] License, *supra* note 104, § 8.2.



formulations, it should be anxious to provide incentives rather than disincentives for generic innovation. One option, obtained in at least one MPP license, is for the MPP to retain the right to negotiate grantback rights for other pool licensees, but with the expectation of royalty or other payments. Nonetheless, there is a complex ecology of providing incentives for originators, incentives for licensee innovation, and competitive dispersion of improved medicines in licensed territories.

*Recommended standard: Where possible, grantback rights should provide some measure of reasonable compensation to the licensee innovator for related improvements and the MPP should, if possible, also receive grantback rights allowing for sublicensing of improvements to other licensees with royalty compensation to the licensee innovator.*

### **G. Other Contract Terms**

#### **1. Separate licenses/license termination/opt-out rights (also called unbundling)**

Licenses for individual APIs or pharmaceutical products could be written as separate licensing agreements, or a license to several products could be bundled into a single agreement. The advantages of separate agreements is that licensees could very easily choose which sublicenses they wanted to enter into and avoid sublicenses where they wanted to. Even when such separate sublicenses are entered into, it is ordinarily desirable for the sublicense to allow termination by the licensee with only minimal notice. At least one license, Gilead HCV License, locks licensees into a minimum five-year term.<sup>232</sup>

Some critics of VLs have been concerned when licenses on different products are bundled together, worrying that this could constitute a form of “tying,” whereby weak patents would be bundled irrevocably with stronger patents.<sup>233</sup> This critique was applied to the MPP/Gilead license even though that license had a provision allowing licensees to unbundle and reject a license on a particular product while maintaining licensed access to other products.<sup>234</sup> Some critics were particularly concerned that companies would not unbundle the TDF license, where patent claims were extraordinarily

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232 Gilead HCV License Agreement, *supra* note 133, § 10.4.

233 See sources cited *supra* note 73.

234 See sources cited *supra* note 73.

weak.<sup>235</sup> These concerns were largely overcome over time. Multiple generic licenses did in fact reject the TDF license and were still permitted to rely on the FTC non-assert agreement to co-formulate TDF and FTC together.

*Recommended standard: Potential licensees should be free to reject particular product patents whether licenses covered multiple medicines or only one, and licensees should also have the right to terminate a particular license contract or the license to particular products subject to notice and accounting to the licensor.*

## 2. Contract enforcement, indemnification, and dispute resolution

VLs frequently give highly specified and enhanced enforcement rights to originator licensors. This is particularly apparent in the recent bilateral hepatitis C licenses negotiated by Gilead, where enforcement rights with respect to product diversion are quite harsh.<sup>236</sup> Because licensors want to protect their commercial interests and their brand's reputation, they use the threat of license termination to ensure that sublicensees heed licensing terms and conditions. They also impose stringent indemnification clauses for liabilities they incur as a result of the licensor's activities.

On the other hand, licensees usually have fairly weak enforcement rights. In the first instance, licensors often make very few affirmative undertakings, mainly to refrain from enforcing exclusive rights. Even more so, except when it is clearly in their commercial interests, generics are reportedly reluctant to enforce contract non-performance against licensors because recouping their sunk costs and earning modest profits is dependent on their continued licensing rights.

It is because of this enforcement imbalance that some critics of the MPP have complained when originator/MPP licenses do not contain some enforcement role for the MPP to help safeguard licensees' interests.<sup>237</sup> Instead, the MPP has opted for engagement and, if need be, less formal dispute resolution in the form of mediation or arbitration when contract disputes arise.<sup>238</sup> Despite

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235 See sources cited *supra* note 73.

236 Gilead HCV License Agreement, *supra* note 133, §§ 6.1(a), 10.3.

237 The MPP might have some stronger contract enforcement rights in its Gilead and BMS licenses as it is a party to those agreements.

238 ViiV-MPP Adult SubLicense Agreement Form, *supra* note 87, § 29.3 (providing for WIPO-rule mediation).

these ancillary remedies for dispute avoidance and resolution, it is desirable that the MPP have explicit rights to participate in license enforcement and settlement.

*Recommended standard: When public health VLs involve intermediaries like the MPP, such licenses should ordinarily provide some enforcement and dispute resolution powers so the intermediary can help to protect the legitimate interests of licensees.*

#### **H. Licensee Responsibilities Concerning Registration and Supplying the Market**

As stated, registration barriers may be every bit as problematic as patent barriers in terms of patients accessing affordable, needed medicines. Not only must medicines be registered in their country of sale and use, but there are also regulatory requirements affecting manufacturing and exporting countries like India that supply a significant portion of generic medicines in LMICs.<sup>239</sup> It is also a standard requirement that MPP licensees obtain regulatory approval from a stringent regulatory authority, WHO prequalification, or temporary approval from a WHO Expert Committee in addition to countries-of-use registration.<sup>240</sup> In the best case scenario, originator companies will undertake accelerated registration of priority medicines worldwide so that no provider or patient in any country must use an inferior medicine or no medicine at all when an essential health need arises. In the real world, however, there are persistent economic and regulatory barriers to universal registration that deter and delay originator registration, e.g., costs of registration dossier preparation and submission, conflicting and unharmonized regulatory requirements and procedures, administrative incapacity and delays, and, in some instances, regulatory corruption.<sup>241</sup> These same realities face follow-on generic registrants, who typically must submit abbreviated data (mainly concerning bio-equivalence or other evidence of therapeutic equivalence and evidence of good manufacturing and distribution practices), but who have smaller

239 V. Senthil et al., *Regulatory Process for Import and Export of Drugs in India*, 6 INT'L J. PHARMACEUTICAL SCI. & RES. 4989 (2015), <http://ijpsr.com/bft-article/regulatory-process-for-import-and-export-of-drugs-in-india/?view=fulltext>.

240 See discussion *supra* Subsection IV.C.4.

241 These costs can be quite significant, especially if one takes into account registering costs in 140 separate LMICs. See Brook K. Baker, *Drug Registration Barriers and Logjams*, in MISSING THE TARGET #5: IMPROVING AIDS DRUG ACCESS AND ADVANCING HEALTH CARE FOR ALL 49–58 (2007).

margins to work with in terms of recouping sunk costs of country-by-country registration. Generic companies might also be wary about product development and registration costs when newly approved medicines have not yet made their way into WHO and national treatment guidelines. Fortunately, MPP and other licenses provide for the licensor to provide information needed for registration and further provide for waiver of data exclusivity and patent-registration linkage rules that might otherwise block registration of a generic equivalent, but significant barriers to registration still remain.

The disincentives to global registration are compounded by the failure to require public dissemination of the registration status of medicines in a global registry or otherwise. Even though medicines registration status is technically a matter of public record in every country, these records are not uniformly accessible online and both originators and generic companies appear to treat registration status as proprietary, confidential information. Unfortunately, at present, even the MPP allows its licenses to provide for registration confidentiality,<sup>242</sup> though it has recently provided some aggregate information on licensees' registration efforts.<sup>243</sup> At this point, only two companies, Gilead and Merck, have publicly disclosed the global registration status of their ARVs and hepatitis medicines on their webpages.<sup>244</sup>

Despite these realities, access licenses should require originators to file for FDA or European Medical Agency approval or WHO prequalification, and to register licensed products in licensed territories at a reasonable but accelerated pace with milestones and

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242 See, e.g., ViiV-MPP Adult Sublicense Agreement Form, *supra* note 87, § 3.5 (requiring reporting on product development, registrations, and registration plans, but providing for confidentiality of the same).

243 *Update on Progress of MPP Licensees*, *supra* note 77.

244 See *HIV/AIDS*, GILEAD, <http://www.gilead.com/responsibility/developing-world-access/hiv%20aids> (last visited June 18, 2018) (access to registration data on page); *Viral Hepatitis*, GILEAD, <http://www.gilead.com/responsibility/developing-world-access/viral%20hepatitis> (last visited June 18, 2018) (access to registration data on page); *Product Registration: MSD Corporate Responsibility Report 2016/2017*, MSD CORP., <https://www.msdrresponsibility.com/access-to-health/product-registration/> (last visited June 18, 2018) (providing MSD registration information on indinavir (no longer recommended), Raltegravir (71 global registrations), efavirenz (86 global registrations), and emtricitabine, tenofovir disoproxil fumarate (34 LMIC registrations)). A review of this limited information reveals a failure to register these products broadly in LMICs.

publicly accessible reporting requirements.<sup>245</sup> Originator licensors should not be permitted to simply wash their hands of registration once they have provided registration-related information and waived data exclusivity and patent-registration linkage, thereby imposing on generic licensees the onerous burden of full-scale registration of a novel product in multiple jurisdictions.<sup>246</sup> It is far easier for a generic

245 MPP licenses do typically impose registration related requirements. *See, e.g.,* ViiV-MPP Adult Sublicense Agreement Form, *supra* note 87, §§ 3.4–3.5 (requiring registration and other regulatory approvals in the territory as soon as practicable with reasonable milestones to be established, and further requiring reporting on product development, registrations, and registration plans); AbbVie-MPP Pediatric Sublicense, *supra* note 107, § 4.2 (imposing reporting requirement on the MPP regarding licensee registration activity); BMS-MPP Agreement, *supra* note 88, § 6(a) (“Each Sublicensee . . . will hold all relevant authorizations and permits . . . .”); BMS-MPP HCV License, *supra* note 124, §§ 5(a), 12.3(b)(iv) (requiring sublicensee to “hold all relevant authorizations and permits” and allowing termination for failure to register licensed products in the territory for all formulations and strengths within 30 months); Gilead-MPP Restated License Agreement in India, *supra* note 90, § 6.2(a) (requiring licensees to apply for WHO prequalification or U.S. FDA approval for COBI, EVG, TAG or BIC within two years of inclusion of such compound in WHO treatment guidelines or an expression of interest of such compound from WHO prequalification, or within three years for combination products); MSD-MPP License Agreement, *supra* note 100, §§ 3.2, 3.4 (requiring licensees to apply for FDA tentative approval, stringent regulatory authority approval, or WHO prequalification within 36 months for existing products and as agreed for new products, and to report on registration status and plans quarterly); ViiV-MPP Adult SubLicense Agreement Form, *supra* note 87, §§ 4.3., 4.5, 13.9 (requiring licensees to obtain and maintain from relevant authorities registrations and other regulatory authorizations within 30 or 36 months and to report on registrations and regulatory filing plans quarterly, and to allow for termination for failure to file for regulatory approval before at least one relevant regulatory authority within 30 or 36 months); ViiV-MPP Pediatric [Sub] License, *supra* note 104, § 3.2–3.3, 12.9 (describing the same provisions as the sections referenced in the immediately preceding license agreement); Pharco-MPP Ravidasvir License, *supra* note 95, §§ 3.3, 5.4(e), 5.4(g) (requiring licensees to commence regulatory filings within 42 months from availability of Phase-III data, and that licensees are responsible for regulatory filings using good faith and diligence); University of Liverpool-MPP Nanotechnology License, *supra* note 95, 18 sched.2.5(B) (“File for regulatory approval needed to ensure access to [i]icensed [p]roducts in the [t]erritory.”).

246 *See, e.g.,* MSF ACCESS CAMPAIGN, BRIEFING DOCUMENT, BARRIERS TO ACCESS AND SCALE-UP OF HEPATITIS C TREATMENT: SPOTLIGHT ON DACLATASVIR 2 (Apr. 2015), <https://www.msfacecess.org/sites/default/files/MSF%20briefing%20document%20on%20BMS%20Daclatasvir.pdf> (noting the absence of a global registration plan); MSF ACCESS CAMPAIGN, MSF RESPONDS TO BMS COMMERCIAL STRATEGY FOR HEPATITIS C

producer to file an abbreviated registration dossier and to achieve an expedited regulatory approval if the originator product has been previously registered. An inferior, but still plausible, alternative is for the originator to provide extensive assistance in the compilation of full registration dossiers.

However, access-oriented licenses should also place obligations on generic licensees. As discussed briefly above, the typical access license imposes quality standards that require registration with a stringent regulatory authority, e.g., the U.S. FDA or European Medicines Authority, or WHO prequalification.<sup>247</sup> Where countries have adopted fast-track registration procedures permitting reliance on stringent regulatory approval or prequalification, the registration process for generics can be greatly accelerated.<sup>248</sup> Licensees should be required to register in a meaningful number of licensed territories—preferably all of them—and they too should be required to report their registration process transparently. Frankly, however, it is also imperative that the global health architecture and countries more rapidly pursue rational regulatory harmonization,<sup>249</sup> and that there

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DRUG DCL IN DEVELOPING COUNTRIES (Nov. 3, 2014), <https://www.msfaccess.org/content/msf-responds-bms-commercial-strategy-hepatitis-c-drug-DCL-developing-countries> (reporting BMS had indicated that it did not have plans to register the drug worldwide); MSF ACCESS CAMPAIGN, ISSUE BRIEF, NOT EVEN CLOSE 7–8 (2017), [https://www.msf.org/sites/msf.org/files/hepc\\_issuebrief\\_hep\\_c\\_2017.pdf](https://www.msf.org/sites/msf.org/files/hepc_issuebrief_hep_c_2017.pdf) (reporting a general failure of BMS and other companies to register their DAAs in LMICs).

247 See discussion *supra* Subsection IV.C.4.

248 For example, many countries have now joined the WHO Prequalification Collaborative Registration Procedure, which accelerates national level registration of WHO prequalified medicines and medicines approved by a stringent regulatory authority. See *Collaborative Procedure for Accelerated Registration*, WORLD HEALTH ORG., <https://extranet.who.int/prequal/content/collaborative-procedure-accelerated-registration> (last visited June 19, 2018). Thirty-three countries have joined the Collaborative Registration Programme for prequalified medicines and 276 registrations have occurred. *Accelerated Registration of Prequalified FFPs*, WORLD HEALTH ORG., <https://extranet.who.int/prequal/content/collaborative-registration-faster-registration> (last visited Jan. 29, 2018). Twenty-one countries have joined the more recently established program for medicines approved by a stringent regulatory authority and 33 registrations have occurred. *Accelerated Registration of FFPs Approved by SRAs*, WORLD HEALTH ORG., <https://extranet.who.int/prequal/content/faster-registration-fpps-approved-sras> (last visited Jan. 29, 2018).

249 Some such efforts are underway with the East African Community and the African Union. See EAST AFRICAN COMMUNITY MEDICINES REGULATORY HARMONIZATION PROGRAMME, <https://www.tfda.go.tz/>



be new mechanisms to assist and accelerate widespread generic registration so as to encourage competitive sources of supply.

Advantages of registration requirements	Disadvantages of registration requirements
<p>Universal or near universal registration is in the best interest of people needing access to affordable medicines and to aggregation of market demand that is most likely to result in robust generic competition and lower prices.</p> <p>Putting obligations on originator licensors eases the burdens of generic licensees who can thereafter submit abbreviated registration applications that can be processed more quickly.</p> <p>Requiring WHO prequalification by licensees is also a best practice that can not only assure quality, but also accelerate in-country registration in many instances.</p>	<p>Registration requirements might not be appropriate when an originator is licensing an upstream medicine and does not intend to commercialize the product itself.</p> <p>There may be situations where the commercial interests and even the capacity of the originator is not congruent with universal registration. In these circumstances, if a duty of universal product registration is imposed, the originator might choose not to license the product or might adversely restrict the licensed territory. Even in these rare instances, obligations to facilitate generic license registration should be undertaken.</p>

In addition to mandating registration requirements, VLS typically impose performance requirements detailing the obligations of licensees to commercialize products in licensed territories. As described with respect to licensee selection, the MPP does a limited review of commercialization plans before approving sublicenses.<sup>250</sup> However, its license and sublicense agreement also contain performance requirements addressing licensees' registration and commercialization responsibilities, though the stringency of these requirements varies considerably from license to license.<sup>251</sup>

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index/?q=node/188; Ndomondo-Sigonda Margareth et al., *The African Medicines Regulatory Harmonization Initiative: Progress to Date*, 6 MED. RES. ARCHIVES 1 (2018), <https://www.journals.kei.org/index.php/mra/article/view/1668/1748>.

250 BMS-MPP Agreement, *supra* note 88, § 2.3(b) (viii).

251 MPP licenses vary performance requirements for generics concerning their duty to commercialize licensed products. *See, e.g.*, ViiV-MPP Adult Sublicense Agreement Form, *supra* note 87, § 10.4 (allowing for termination upon reasonable opinion of licensor that licensee has failed to make reasonable



*Recommended standard: Access licenses should ordinarily impose reasonable registration requirements on both licensors and generic licensees, including that licensors should assist and help facilitate regulatory filing by licensees. Licenses should also impose reasonable performance obligations on licensees with respect to commercializing affordable medicines in a significant portion of the licensed territory.*

### **I. Publication of Licenses and Transparency of Patent Landscapes**

Commercial and bilateral VLs are almost never published by the parties, with the limited exception of Gilead's indirect publication of its HCV license and its 2006 TDF license. In contrast, the MPP has established a total transparency standard by publishing both the licenses and sublicenses and, more recently, reviews by its Expert Advisory Group.<sup>252</sup> Opening access licenses to scrutiny allows informed feedback on licenses from civil society and other experts,

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progress in promoting access pursuant to the license); BMS-MPP Agreement, *supra* note 88, §§ 5(c), 6, 13.3(b)(iii) (requires licensee to take all reasonable efforts to provide an adequate supply of licensed products to meet therapeutic needs in the territory, use all reasonable efforts to provide a sufficient supply and submit good faith proposals in response to tenders, and develop and commercialize licensed products within three years); BMS-MPP HCV License, *supra* note 124, § 4(c) (licensee is required to take all reasonable efforts to provide an adequate supply of licensed products to meet therapeutic needs in the territory); Gilead-MPP Restated License Agreement in India, *supra* note 90, § 6.1 (purpose of the agreement is to increase patient access to licensed products, but licensee has the sole discretion to manage its own commercial strategy); MSD-MPP License Agreement, *supra* note 100, §§ 3.4, 10.4 (report on registration status and plans quarterly; termination upon reasonable opinion of licensor that licensee has failed to make reasonable progress in promoting access pursuant to the license); ViiV-MPP Adult Sublicense Agreement Form, *supra* note 87, § 13.10 (termination upon reasonable opinion of licensor that licensee has failed to promote access pursuant to the license after notice of same); ViiV-MPP Pediatric [Sub] License, *supra* note 104, § 12.10 (same); Pharco-MPP Ravidasvir License, *supra* note 95, § 5.4(g) (licensee shall use all reasonable efforts to provide an adequate supply of licensed products to meet therapeutic needs in the licensed territory, to provide strong supply and distribution, and to promote affordable access); University of Liverpool-MPP Nanotechnology License, *supra* note 95, at 18 sched.2, 23 sched.4, 26 sched.5 (describing anticipated formulation, quality, registration, and commercialization/distribution by any Development Partner licensee).

252 *Products Licensed*, *supra* note 80 (providing links to pages for licensed medicines where licenses and Expert Advisory Group reports are available); *see also Expert Advisory Group Reports*, MEDS. PATENT POOL, <https://medicinespatentpool.org/who-we-are/governance-team/expert-advisory-group/eag-reports/> (last visited June 17, 2018).

which in turn can lead to improvements in the MPP's licensing practice. As discussed in preceding subsections, there are multiple examples of where informed civil society feedback has pointed out problems allowing recalibration of licenses, e.g., changes to compulsory licensing provisions and non-assert clauses in Gilead's 2011 MPP license, royalty coverage for only granted patents in ViiV and AbbVie licenses, expansion of direct and indirect licenses in multiple licenses, and others.

*Recommended standard: Public health VLs should be published in fully accessible form, preferably on the internet. Such disclosure fosters transparency and accountability and enables constructive feedback that can lead to license improvements.*

A major problem confronting potential government policy makers, generic entrants, and procurers is determining the patent landscape on particular medicines. Although patents theoretically require publication, in fact determining patent status of medicines can be extraordinarily difficult. Although patent landscapes may be contained within bilateral commercial licenses, these licenses are not publicly accessible.<sup>253</sup> Thus, it is an enormous advantage that the MPP has succeeded in requiring originators to disclose the patents that are pending or granted in licensed territories. Indeed, in at least two instances, the MPP has succeeded in convincing the licensor to disclose its global patent landscape.<sup>254</sup> This added information is quite helpful to advocates, countries, and generic companies weighing strategies to create generic competition alternatives even in non-licensed territories. In addition, the MPP has also recently launched its MedsPaL database containing information on patent and licensing status of selected HIV, hepatitis C, tuberculosis, and other essential medicines in LMICs where such information could be obtained.<sup>255</sup> Other multilateral organizations are also providing useful information on patents and patent landscapes.<sup>256</sup>

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253 See *supra* Subsection IV.B..

254 See *supra* text accompanying note 133.

255 MedsPaL: *The Medicines Patent and Licenses Database*, MEDS. PATENT POOL, <http://www.medspal.org> (last visited Jan. 26, 2018).

256 Unitaid and the WHO have also issued publications addressing patent landscapes on some key medicines. See Search Results for 'Patent Landscape', UNITAID, <https://unitaid.eu/?s=patent+landscape#en> (last visited June 17, 2018); see also WHO *Updates Patent Information on Treatments for Hepatitis C*, WORLD HEALTH ORG., [http://www.who.int/phi/implementation/ip\\_trade/](http://www.who.int/phi/implementation/ip_trade/)

*Recommended standard: Public health VLs should require licensors to disclose their patent landscape, especially in licensed territories, but also in non-licensed territories as well.*

#### **J. Opportunities to Improve or Amend Existing VLs**

Access licenses are unlikely to be perfect and thus opportunities for amendment should be supported. Originators, on occasion, have amended their own bilateral, quasi-commercial licenses on their own initiative or in response to public criticism.<sup>257</sup> As discussed previously, the MPP has also been successful in amending several of its licenses to expand access.<sup>258</sup> Sharing a commitment to improving licenses—and licensors and licensees being open to the same—is vitally important to the ultimate public health goals of VLs.

*Recommended standard: Access licensing terms and conditions should be open to amendment in response to public health needs and informed critique.*

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ip\_patent\_landscapes/en/ (last visited June 17, 2018), for a webpage with access to five Unitaaid patent landscapes. See also WHO Updates Patent Information on Treatments for Hepatitis C, WORLD HEALTH ORG., [http://www.who.int/phi/implementation/ip\\_trade/ip\\_patent\\_landscapes/en/](http://www.who.int/phi/implementation/ip_trade/ip_patent_landscapes/en/) (last visited June 17, 2018), for a webpage with access to five Unitaaid patent landscapes. The WIPO and the International Federation of Pharmaceutical Manufacturers and Associations, in collaboration with 20 pharmaceutical companies, recently announced their intent to establish a pharmaceutical patent database as well, which will list granted patents for small molecule products within oncology, hepatitis C, cardiovascular, HIV, diabetes, and respiratory therapy areas; and any products on the WHO Essential Medicines List that are not within these therapy areas. See World Intellectual Prop. Org., *Patent Information Initiative for Medicines (Pat-INFORMED)*, PATENTLY-O (2017), <https://patentlyo.com/media/2017/10/Pat-INFORMED-backgroundunder-FINAL.pdf>. Concerns about conflict of interest and incomplete disclosure have already been raised. K.M. Gopakumar, *IFPMA-WIPO Partnership Raises Conflict of Interest Concerns*, THIRD WORLD NETWORK: TWN INFO SERVICE ON IP ISSUES (Oct. 9, 2017), [https://www.twn.my/title2/intellectual\\_property/info.service/2017/ip171003.htm](https://www.twn.my/title2/intellectual_property/info.service/2017/ip171003.htm).

257 Mara, *supra* note 74.

258 See, e.g., sources cited *supra* note 75; Gilead, *supra* note 76.

## V. Conclusion: Complementarities and Conflicts Between VLs and Other Access Strategies<sup>259</sup>

At present, much of the criticism of VLs, including those negotiated by the MPP, focuses on the alleged negative impact of licenses on the use of other TRIPS-compliant flexibilities, including IP reform, oppositions, and compulsory licenses. Voluntary licensing strategies have been called “industry-controlled” and devices to “control competition” by dividing markets.<sup>260</sup> They have also been questioned about whether they are well-timed, both with respect to licensing of weak patents that might be successfully opposed or otherwise challenged in key LMICs, including India, and with respect to product registration and guideline adoption decisions that are crucial to understanding the market potential of newer medicines. Opponents have also been concerned about favorable publicity that innovators have received over their humanitarian VLs and about the reality that their preferred strategies, especially oppositions and compulsory licenses, have received less donor support from Unitaid and other entities. On the other hand, defenders of VLs, and most especially MPP licenses, have argued that VLs speed access

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259 In the discussion *supra* that follows, much of which has been gleaned not only from sources cited *supra* notes 72–73, but also attendance at multiple international and regional forums with access-to-medicines advocates and many email exchanges, the author chooses not to directly identify sources for particular positions critical of VLs. However, the author does try to respond to critiques that have been strongly and repeatedly expressed by some within the access movement.

260 Concerns about VLs being industry-led and market-dividing seem rhetorical, inaccurate, and incomplete. The entire international IP regime codified in the TRIPS Agreement is industry-driven. As a matter of historical fact, a patent pool for medicines was conceptualized by civil society advocates and later promoted and advanced by a coalition of treatment access groups, including MSF and others. The industry has been a relatively reluctant partner, as shown by the significant lag in many companies joining the Pool and then only on narrow terms, i.e., only for pediatric licenses. Similarly, to say that VLs are market-dividing is both true and misleading at the same time. All known public health licenses exclude virtually all upper-income countries, countries where some poor people also live and where access needs can be acute, but licenses are not criticized on that basis. Instead, they are criticized for excluding other, mostly upper-middle income countries where originators have profit-driven commercial interests. However, the licenses grant and increase competitive access in many LMICs directly and indirectly at the same time they maintain exclusive access in excluded countries. Why is it more appropriate to say that licenses divide markets rather than that they shrink exclusive, monopoly-controlled markets while legitimizing competitive generic access in other markets?

to newer medicines to a significant number of people living with HIV, and that MPP licenses do not in fact undermine other access strategies. From the very beginning, key proponents have argued that MPP VLs are only part of an overall access strategy and that licenses are complementary to other strategies and can work with them synergistically rather than antagonistically. Thus, an important issue to address is whether VLs, like those negotiated by the MPP, are antagonistic or complementary to other access strategies and how they fit into an overall access strategy in terms of prioritization.

To date, these debates have perhaps been more ideological than is desirable. Opponents, for example, have argued in some forums that oppositions and compulsory licenses are superior because they take power away from pharmaceutical companies and force governments to actualize the right to health. They have also argued that voluntary licensing strategies create the false impression that access concerns have been met; that more broad-sweeping reforms of intellectual property exclusivity and of the innovation/access ecology need not be enacted (for example by delinking the market for R&D grants and prizes from the access market of competitive supply of medicines of assured quality); and that equity concerns—access for all—can be ignored. In addition, they have argued that MPP licensing negotiations should be more open to inputs from civil society advocates, patient groups, and affected governments. Finally, they argue that the MPP should have a stronger set of conditionalities on licenses, including, for example, expanded territorial coverage, exclusions on royalty payments, freedom to source APIs, and denial of territorial controls based on pending patents. Proponents, in contrast, have argued an ideology of pragmatism—that all gains in the access movement have been incremental and incomplete, that industry must be dealt with within the existing legal terrain where it often has the upper-hand, and that partial victories, especially those reaching nearly 90% of people living with HIV, should not be discarded because 10% are left to other strategies. Proponents of VLs are also skeptical that the alternative, country-by-country and government-dependent strategies are superior and that they cannot in fact deliver broad scale access and aggregate markets in any reasonable time frame.

This analysis has already addressed many of the questions raised by skeptics of VLs, though not all of them. Several unaddressed criticisms, however, may carry weight and should be addressed.

First, if public health VLs give false assurance that the totality

of the access crisis has been met for ARVs, then this could have negative impacts for civil society activism and government action. The MPP is always careful, however, to stress that it sees itself as only part of the solution to inadequate, delayed, and unaffordable access to needed medicines of assured quality. And virtually all compulsory license commentary, by opponents and proponents, has also made this point. At present, there is very little direct evidence linking government action or inaction to the existence of VLs, but such evidence should be gathered. It will certainly behoove the access movement to continue to describe the gaps left by VLs, the need for further efforts with alternative access strategies, and the need for more fundamental reforms to pharmaceutical IP hegemony and to the ecology of innovation and access.

Second, if public health voluntary licensing strategies soak up the bulk of the resources that could go to needed IP-related strategies, this too is a concern. Of course, it is by no means certain that the counterfactual is true—that if the money did not go to the MPP it would have gone to other IP-access strategies instead. And, since 2011, Unitaid in particular has begun to finance other IP-related access strategies, including oppositions and compulsory licensing,<sup>261</sup> though it has not yet provided direct support for patent reform projects. Civil society delegations within Unitaid waged a four-year campaign for Unitaid to develop an IP strategy, which resulted in the adoption of an Intellectual Property Approach in 2016,<sup>262</sup> and the launch of an IP call for proposal shortly thereafter with a projected budget of \$15 million.<sup>263</sup> At this point it is hard to say that the MPP has been getting too much money, though it may well be fair to say that alternative strategies continue to get too little.

Third, in terms of “correct” timing, the timing of VLs before

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261 *Affordable Antiretroviral Drugs for Middle-Income Countries*, UNITAID, <https://unitaid.eu/project/itpc-affordable-avrs-middle-income-countries/#en> (last visited June 17, 2018); *Overcoming Patent Barriers for Antiretrovirals*, UNITAID, <https://unitaid.eu/project/overcoming-patent-barriers-antiretrovirals/#en> (last visited June 17, 2018).

262 UNITAID, *UNITAID’S APPROACH TO INTELLECTUAL PROPERTY* (2016), <https://unitaid.eu/assets/UNITAID’s-approach-to-Intellectual-Property.pdf>.

263 Press Release, Unitaid, *Unitaid Invites Proposals that Help Countries Use Trade Rules to Increase Access to Drugs* (Feb. 20, 2017), <https://unitaid.eu/news-blog/unitaid-invites-proposals-help-countries-use-trade-rules-increase-access-drugs/>; *Call for Proposals: Supporting Access to Medicines*, UNITAID (Aug. 17, 2017), <https://unitaid.eu/call-for-proposal/supporting-access-medicines-innovative-use-trips-flexibilities/#en>.



patent decisions and before originator product registration entails trade-offs. Yes, licenses can be granted on the basis of pending patents—patents that might be weak and opposable, but in any event patents not yet granted. They have also been granted for medicines that have not yet received regulatory approval or worked their way into treatment guidelines. Thus, generic licensees may begin to make investments in promising, but unconfirmed products and those costs may be disproportionate market realities and health needs. These risks and losses might interfere with their investments in other product needs. On the other hand, delay has risks as well. Before the MPP became active in licensing, the average time-to-market of “new” ARVs was 8+ years after product introduction in rich country markets.<sup>264</sup> That delay is now being significantly reduced, both because of quicker licensing and registration of already approved products, but also because of preliminary work done on pipeline products.<sup>265</sup> Moreover, the costs of delay can be real: newer and improved medicines can save lives.

Fourth, equitable concerns about excluded countries, or more accurately, excluded people, are real. The access community espouses universal access and special programming to reach neglected, vulnerable, and most-at-risk populations. Nonetheless, the principle of full equity has to face the moral challenge of access for none. Is it really preferable that 90% of people living with a disease must wait for life-saving medicines until medicines are affordably available for all? Shouldn't we instead fight for accelerated access for excluded people while still ensuring access for those whose needs could be met through VLs?

Fifth, if public health VLs negatively impact opposition strategies and opposition decisions in national patent offices, this could be a problem. At this point, there is little doubt that VLs undermine incentives to generic companies to initiate or pursue oppositions, particularly after a VL has already been negotiated. Accordingly, unless access and public-interest groups are funded to continue oppositions, there might well be a future drop-off in opposition filings. Since some countries have big enough and affluent enough markets that opposition strategies are attractive options,

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264 MEDS. PATENT POOL, PROGRESS AND ACHIEVEMENTS OF THE MEDICINES PATENT POOL 7 (Nov. 1, 2015), [https://medicinespatentpool.org/uploads/2017/07/MPP\\_Progress\\_and\\_Achievements\\_Repor\\_EN\\_2015\\_WEB.pdf](https://medicinespatentpool.org/uploads/2017/07/MPP_Progress_and_Achievements_Repor_EN_2015_WEB.pdf).

265 *Id.*



undermining oppositions should be avoided. This is particularly true in key producer countries where successful oppositions can have multiplier effects creating access opportunities in the many LMIC markets where there are no domestic patents blocking access. On the other hand, there are other features of opposition strategies that make them less than ideal, especially as a stand alone option:

- Not all LMICs have adopted opposition procedures and relying on alternative court-based invalidation proceedings is so costly and time-consuming as to be impractical in most LMICs.
- It is difficult to discern which filed patents are likely to be blocking with respect to future marketed medicines, both because patents are often filed at the early R&D stage before safety and efficacy are established,<sup>266</sup> and because patent disclosure rules do not currently make it easy to identify all the product, process, and method-of-use patents<sup>267</sup> that might be relevant to an ultimate finished product.
- Patent applicants can deploy many strategies to draw out and frustrate opposition strategies by filing additional, potentially blocking patent applications, using patent division and patent selection strategies, and appealing adverse decisions.<sup>268</sup>
- Opposition strategies require expert resources and political energy. Even though emerging opposition networks are sharing expertise and strategies, capacity challenges and expenses still exist.
- Most significantly, oppositions are country-by-country and thus it is difficult to amass aggregated markets that are attractive to multiple generic entrants.

It might be important to discover whether exclusion from VLs is not in fact strengthening government resolve in excluded countries to make efficient use of rigorous patent examination and

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266 Even diligent opposition networks have missed filing oppositions on some important candidate products. For example, TAF in India is now poised to replace TDF as a preferred product because of its reduced costs and better side-effect profile.

267 Activists should certainly pursue patent law reform that excludes new use/method-of-use patents, but the reality is that they are still granted in many jurisdictions.

268 There have been a large number of very important opposition victories in India, but those were partially an artifact of its extended transition period and its mailbox provisions, which allowed oppositions to be filed after 2005 for patents on products that had already come to market and shown their market and public health potential.

opposition opportunities.

Sixth, if public health VLs were to negatively impact compulsory licensing strategies, especially in countries excluded from VLs, that too could be a problem. One of the main issues that critics are concerned about is that most of the quality generic producers will be drawn to the temptation of easy-to-secure VL territories and that they will have reduced incentives to seek compulsory licenses in excluded countries. Even worse, major generics could become so tied, pragmatically, if not legally, to originators that none of them would want to “cross” their licensing partners by seeking or accepting compulsory licensee status. In the worst case scenario, there would be no qualified generics producers left to serve excluded countries. Maintaining, indeed strengthening, compulsory licensing options remains important, especially in excluded countries, but could also be needed even in included countries under some licenses if export permissive compulsory licenses to non-included countries must be secured. It is important to reemphasize that the MPP scrupulously protects its licensees’ right to prosecute compulsory licenses or to otherwise become compulsory licensees. It is also appropriate to note that compulsory licensing strategies cannot always bypass the VL option. This is because Article 31 of the TRIPS Agreement requires prior negotiation on commercially reasonable terms for a commercially reasonable time, except in circumstances of publicly declared emergency or urgent need, public, non-commercial use, or competition remedy. Thus, originators have it within their power to select VLs even in common cases where compulsory licenses might be pursued. Similarly, like with opposition strategies, compulsory licensing strategies face some challenges:

- They can be plagued by delays and appeals, but they can also be blocked by government indifference, inaction, and political constraint.<sup>269</sup>
- They too need to be pursued country-by-country and product-by-product, making it difficult and uncertain that significant markets can be aggregated except in the largest population countries.
- Compulsory licenses are also reviewable, potentially delaying their implementation, and can be revoked when the grounds

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<sup>269</sup> India, for example, seems to have instituted what is hoped to be only a temporary moratorium on issuing compulsory licenses in response to intense pressure by the U.S. government over its IP policies, including the issuance of just one pharmaceutical compulsory license to Natco on a Bayer cancer medicine.

justifying their issuance have changed. Thus, there is some possibility that originators might offer reduced pricing or engage in some degree of local manufacture, and thus undermine the compulsory license itself.

- In truth, compulsory licenses have been rarely utilized thus far by countries typically excluded from VLs.<sup>270</sup>

In conclusion, despite the importance of compulsory license options to secure alternative sources of supply, to push originators into VLs, or to negotiate price reductions and perhaps technology transfer, compulsory licenses, like oppositions and VLs, remain incomplete options.<sup>271</sup>

If all access options are imperfect and incomplete, does that mean that they are antagonistic or does it mean that they can be complementary and must be deployed strategically? If VLs secure robust generic competition in the bulk of LMICs, can't access activists use oppositions and VLs to gain access in a much smaller set of excluded countries? Doesn't the threat of compulsory licenses incentivize originators to include new countries in the licensed territory? Doesn't the success of oppositions potentially reduce originators' claims to exclusive rights thereby affecting their ability to control API supplies, to limit countries of production, and to collect royalties? The answer to all of these questions seems to be affirmative. The few affirmative impediments identified—anti-diversion barriers to parallel importation and reduced incentives for generics to file oppositions—do not seem to override the many synergies that exist. This does not mean that the principled efforts to improve the access terms of VLs should not continue, nor does it mean that efforts to construct stronger forms of collaboration and cooperation between LMICs with respect to patent law reform,

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270 Thailand issued seven government-use licenses between 2006–2007 on ARVs, cardio-vascular, and cancer medicines but none since; Brazil issued one compulsory license on an ARV in 2007; India issued one compulsory license on a cancer medicine; Ecuador has issued multiple compulsory licenses; and Indonesia has recently issued seven government-use licenses on HIV and hepatitis B medicines. Given the breadth of need, not only for HIV medicines, but for medicines across the entire health spectrum, this is a paltry total.

271 One option to strengthen the compulsory license alternative is new proposals to make compulsory licenses automatic or at least routine and to develop a facility or platform to coordinate the issuance of compulsory licenses. See Brook K. Baker et al., *Compulsory License Facility*, U.N. SEC'Y GEN'S. HIGH-LEVEL PANEL ON ACCESS TO MED. (Feb. 27, 2016), <http://www.unsgaccessmeds.org/inbox/2016/2/27/brook-baker>.

patent oppositions, and compulsory licenses should not be pursued. But it does suggest that the partial fracture that has developed in the access movement might be reduced or eliminated if activists were to acknowledge and pursue the complementarity of approaches rather than rhetorically berating any particular strategies.

Despite this perhaps optimistic conclusion, it remains true that the access movement needs more evidence on the public health benefits and possible negative impacts of VLs. We need to know if the availability of VLs is undermining LMIC commitment to adopting and using other TRIPS-compliant public health flexibilities. For example, we need to know if India's threatened retreat on pro-health IP policies is even partially attributable to its inclusion in key VLs and its preferential placement as a key generic supplier. As another example, we need to know if Brazil's pursuit of weaker short-term access and pricing terms in exchange for longer-term negotiated access to technology-transfer/capacity-building is a wise strategy or not. Accordingly, the tentative recommendations and conclusions of this article must continue to be open to evidence, revision, and review.



