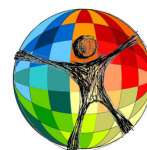


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# **Adopting Universal Design in Disability Policy: An Approach to Centering People with Disabilities**

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# ABSTRACT

Conceptions of *disability* vary across time and cultures, and directly influence which rights are granted to people with disabilities and how. Following the introduction of the United Nations' 2006 *Convention on the Rights of Persons with Disabilities* (CRPD) to the international stage, policy reforms to the legal capacity of people with disabilities have led to a call for jurisdictions to shift from substitute decision-making to supported decision-making frameworks.

This paper describes how existing academic models frame the autonomy of people with disabilities, explores the tensions that arise when decision-making frameworks shift, and considers how the architectural theory of universal design can help better integrate supported decision-making into existing legal regimes. Modern conceptions of disability reflect what disability advocates have petitioned for over generations: moving toward championing the human rights of people with disabilities in all regards. From a legal standpoint, the CRPD reflects this conception of disability. Yet, human rights-centred approaches to issues in disability also exist outside of the law, allowing an interdisciplinary approach to understanding disability.

For example, the architectural Principles and Goals of universal design can push people to think about design in a person-centred way. The Goals of universal design may serve as inspiration for a concrete way in which to implement sweeping reforms in disability law and policy, as they can be abstracted from their context and applied to policies. In this way, countries that hesitate to reform their decision-making frameworks could have more guidance on how to orient their policies to best serve the human rights of people with disabilities, without having to face the drawbacks of systemic overhaul.

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## Introduction

### *Observing shifts in legal regimes*

During the summer of 2021, I took part in an internship dealing with disability law at the Pontificia Universidad Católica del Perú (PUCP) in Lima. Disability law has changed substantially over the past few years in Peru following reforms to the Peruvian Civil Code.<sup>1</sup> These reforms implemented recommendations made by the United Nations' *Convention on the Rights of Persons with Disabilities* (CRPD) and dramatically expanded the rights allotted to people with disabilities,<sup>2</sup> including full legal capacity and the option for supported decision-making, wherein the will of people with disabilities is central in the decision-making process.<sup>3</sup> This represents a break from the previous regime, which touted substitute decision-making for people lacking legal capacity, allowing curators to make decisions for people with disabilities. The implications of the reform are still being ironed out, and I had the opportunity to see systemic changes in action, and observe issues with their implementation.

Though the internship was remote given the COVID-19 pandemic, I was able to partake in a legal clinic at the PUCP's Institute for Democracy and Human Rights (IDEHPUCP) that

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<sup>1</sup> See Legislative Decree No 1384 (Peru) (last accessed 18 August 2022), online (pdf): <[sodisperu.org/sites/default/files/2021-05/Legislative-Decree-No-1384-Peruvian-legal-capacity-reform-2.pdf](https://sodisperu.org/sites/default/files/2021-05/Legislative-Decree-No-1384-Peruvian-legal-capacity-reform-2.pdf)> [Decree 1384].

<sup>2</sup> Terminology matters when discussing disability. In this essay, I have chosen to write primarily in a person-centred way, using the term “people with disabilities,” though many people use the term “disabled people” as well. The choice of words to describe a person should ultimately fall to them, as each person may have a preference in describing themselves in relation to their disability.

<sup>3</sup> See *Convention on the Rights of Persons with Disabilities*, 30 March 2007, UN GAOR, 61st Sess, Annex I, UN Doc A/RES/61/106, 46 ILM 443 [CRPD]; Lucy Series and Anna Nilsson, “Article 12 CRPD: Equal Recognition before the Law” in Bantekas, Stein & Anastasiou, eds, *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (London: Oxford University Press, 2018) at 3-4.

helped people with disabilities navigate the legal system.<sup>4</sup> My team and I worked with a few different clients, but we spent most of our time on one case: that of a young man with Down's Syndrome seeking to acquire more financial contributions from an estranged father.

Under the previous substitute decision-making regime, this man would have had a guardian request these contributions and allot the money as they saw fit, ideally in his best interest. That guardian would have probably been his mother, with whom he lives. There would not have been much of a difference in his legal autonomy between childhood and after he turned eighteen.

Under the reformed decision-making regime, he has been recognized as having full legal capacity. He was cautiously excited about this, as most young adults may be when they are granted full rights. However, given his disability, he was aware that there were dimensions to the requests process that he did not understand. In these circumstances, he looked to his mother for support.

Effectively, the young man appeared to want to shift this legal responsibility onto his mother. She would act as his legal representative, an *apoyo*. Some may think he would have been happy with the previous system where his mother would have remained his guardian for his entire life. After all, here he was asking for her to take over. However, the differences between the past and current systems are enormous. When we met with him to understand why he wanted to designate his mother as his *apoyo*, he was happy to discuss his life, to explain to us his relationship with her, to tell us how much he trusted her. He chose her—willingly, of his own volition—to represent him in something. He wanted her support.

All of us at the clinic agreed that he seemed capable enough to pursue the requests process himself, even though he was happy to let his mother do it. The principal reason he and his mother had actually come to us was because the court had requested it. A judge had asked that the young man seek an *apoyo* in an effort

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<sup>4</sup> See Instituto de Democracia y Derechos Humanos, "IDEHPUCP" (2017), online: IDEHPUCP—Instituto de Democracia y Derechos Humanos PUCP <[idehpucp.pucp.edu.pe/](http://idehpucp.pucp.edu.pe/)>.

to streamline the requests process. We could have opposed this decision based on his capacity to understand the process, but the young man needed funding, not a legal battle. To me, the judge's request for an *apoyo* where it wasn't necessary was a sign that the Peruvian legal system was struggling to accept the full legal capacity of people with disabilities.

Of course, this is only one example. However, it made me think about the efficacy of sweeping legal reforms. Are these better than incremental changes that follow evolving social mores?<sup>5</sup> What is the use of a law that people don't understand, or respect? Why wasn't the court willing to have the young man engage with the judicial process himself? Why did the court prioritize streamlining bureaucracy over the human rights of this individual?

This essay will explore how to remedy legal progress in the field of disability rights with slow-moving shifts in conceptions and attitudes surrounding disability. My hypothesis is that some jurisdictions need a transition phase to adjust to systemic overhaul. This transition would begin with an introduction to the social and philosophical principles underpinning new legislation. In this case, these principles would be the value of human rights for people with disabilities. Eventually, these principles would integrate into the social, political, and economic fabric of society, aided by time, education, and social engagement, among others. Changes in law would thereafter be welcomed as obvious, reflecting accepted changes to social mores. I worry that, otherwise, by introducing sweeping changes to systems that aren't open to receiving them, the value of progressive law could be overshadowed by its failures in implementation. This may discredit a valid framework that disability advocates have been fighting for over generations.

### *Representation matters*

The shift in Peruvian law followed the CRPD's recommendations, which called to reform laws concerning people with disabilities.<sup>6</sup> On the international stage, disability advocates

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<sup>5</sup> See Martha L Minow "Brown v. Board in the World: How the Global Turn Matters for School Reform, Human Rights, and Legal Knowledge" (2013) 50 San Diego L Rev 1 at 3.

<sup>6</sup> See CRPD preamble and art 12, *supra* note 3.

have worked hard to change the narrative around disability and human rights.<sup>7</sup> In many societies, our views of people with disabilities have changed over time, but this is not a universal shift and cultural differences in interpretation will always remain. Historically, people with disabilities have often been cast aside, and deemed not to have the same rights as anyone else.<sup>8</sup> They have historically not been given a voice or proper representation in society. This deprivation of rights has made this group particularly vulnerable to human rights abuses, which the CRPD sought to address in its Declaration.<sup>9</sup>

People with disabilities have long advocated for more rights, and the CRPD represents a success story within international disability advocacy circles.<sup>10</sup> The drafting of the Declaration was done in cooperation with groups of disability advocates, and people with disabilities were represented on the international stage.<sup>11</sup> They were given a voice.

After the CRPD's adoption, many State parties had differing interpretations of what the Articles within it called for.<sup>12</sup> Many countries ratified the CRPD, but added qualifications clarifying their own interpretations.<sup>13</sup> These disagreements stem from differing conceptions of disability within cultures faced with the rigid, prescriptive guidelines given by the CRPD. Though some countries, like Peru, have opted to change their regimes regarding disability, others, like Canada, have hesitated to fully implement this reform.<sup>14</sup> This has led to a continuous conflict of values and interpretation between countries, the drafters of the CRPD, lawmakers, and disability advocates.

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<sup>7</sup> See Series, *supra* note 3 at 4.

<sup>8</sup> See CRPD, *supra* note 3 at preamble.

<sup>9</sup> See *ibid.*

<sup>10</sup> See Series, *supra* note 3 at 3.

<sup>11</sup> See *ibid* at 4.

<sup>12</sup> See *ibid* at 8.

<sup>13</sup> Legal capacity is discussed in Article 12 of the CRPD. This will be expanded upon later (see CRPD, *supra* note 3, art 12).

<sup>14</sup> See Decree 1384, *supra* note 1.

In addition to being historically denied basic rights, people with disabilities remain excluded from social, political, and economic life in many ways. One of the mechanisms of societal exclusion of people with disabilities is exclusion from physical space. Urban design and architecture can sometimes be exclusive of people with physical disabilities, because spaces are not designed with them in mind.<sup>15</sup> As a result, people with disabilities have trouble accessing certain locations that people without disabilities have no trouble reaching. In places that people with disabilities cannot physically access, they lack representation. When people with disabilities lack access to essential services like schools, hospitals, and voting centres, this erasure has devastating effects. They lose opportunities to participate in society.

The world of architecture has sought to solve this issue through the concept of universal design, which aims to design space from a person-centred point of view.<sup>16</sup> The seven Principles and eight Goals of universal design push architects and urban designers to consider who they are constructing a space for. They also invite them to include people with disabilities in their thought process. The Principles were initially published in 1997, but, after observing that they were overly prescriptive and not sensitive enough to cultural differences, they were complemented by the Goals in 2012.<sup>17</sup>

### *Adopting person-centred design in policy*

The insightful Goals of universal design are general enough that they can be expanded to apply outside of the realm of architecture and urban design. The Goals may help people with disabilities, as they push people to think in a person-centred way. They could help policymakers design laws and regulations more

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<sup>15</sup> See Jordana Maisel & Molly Ranahan of the WBDG Accessibility Committee, "Beyond Accessibility to Universal Design" (2017), online: *Whole Building Design Guide* <[www.wbdg.org/design-objectives/accessible/beyond-accessibility-universal-design](http://www.wbdg.org/design-objectives/accessible/beyond-accessibility-universal-design)>.

<sup>16</sup> See Ron Mace et al, "The Principles of Universal Design" (4 January 1997), online: *North Carolina State University* <[projects.ncsu.edu/ncsu/design/cud/about\\_ud/udprinciplestext.htm](http://projects.ncsu.edu/ncsu/design/cud/about_ud/udprinciplestext.htm)>.

<sup>17</sup> See *ibid.* See also Edward Steinfield & Jordana Maisel, *Universal Design: Creating Inclusive Environments*, 1st ed (Hoboken, New Jersey: John Wiley & Sons Inc, 2012) (ProQuest).

inclusively. Furthermore, when faced with disagreements in interpretation, as is the case with Article 12 of the CRPD, the universal design Goals may help frame how to best move forward. Perhaps, in lieu of overhauling regimes entirely, we can focus on integrating the human rights of people with disabilities by designing existing policies in a person-centred way.

This paper seeks to explore how the Goals of universal design can be repurposed to guide better implementation of the CRPD within different legal regimes. Part I will review the three main conceptions of disability (the biomedical model, the social model, and the human rights model) and the role that cultural interpretations play in approaches to disability. Part II will cover the birth of universal design and consider how to implement person-centred design beyond the physical realm. Part III will consider how the Goals of universal design can improve implementation of the CRPD's recommendations in different societies. I offer a solution that moves away from prescriptive norms, and, instead, implements culturally appropriate changes within societies that champion the human rights of people with disabilities.

## **PART I. Achieving a human rights-centered definition of disability**

Historically, societies have adopted attitudes toward disability that have dehumanized and stigmatized people with disabilities. People with disabilities have been singled out because they exist in the world in a different way than the expected norm due to their physical or intellectual differences. In the 1960s, Michel Foucault took account of the archaeological history of what he called *insanity* from the Renaissance to the modern era. He concluded that perceptions of insanity were influenced by contemporary culture, social context, historical moments, and laws, among others.<sup>18</sup> Essentially, Foucault posited that insanity—a term he used to refer to disability, particularly intellectual disability—can be abstracted only in the socio-historical context in which it is encountered. Indeed, defining *disability* immediately presents difficulties in abstraction, and it is essential to bear in mind that definitions are temporally linked to cultural and historical contexts. Thus, we can expect to encounter different definitions of *disability* throughout history, but also across different cultures.

Despite differences in conceptions of disability, we must achieve a working definition of *disability* that can allow for substantive human rights to flourish. Agreement on what *disability* means and how it affects people is a precondition to working towards a better life for people with disabilities. I assume here that societies—despite cultural differences—agree on some basic philosophical and moral level that all people have inherent dignity and are worthy of equity, respect, and self-realization. This assumption isn't as easily extended to people with disabilities, as the history of disability is fraught with the systematic denial of the human rights of people with disabilities through frameworks of paternalism and protectionism.<sup>19</sup> However, the advent of the CRPD and the increasing representation of the voices of people with disabilities in academic, political, and legal conversations

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<sup>18</sup> See Michel Foucault, *Madness and civilization: a history of insanity in the age of reason*, 1<sup>st</sup> ed (New York: Vintage Books, 1961).

<sup>19</sup> See Jonas-Sébastien Beaudry, "The Vanishing Body of Disability Law: Power and the Making of the Impaired Subject" (2018) 31 Canadian Journal of Family Law 7 at 14.

give me hope that we can engage in discourse about disability with this basic assumption in mind.

Here I introduce three main conceptions of disability, or *models* of disability, which can be used as frameworks for conceiving of disability in relation to society.

### *The biomedical model of disability*

The first model I will describe is the biomedical model, which posits that disability is an impairment that a person experiences, and that it may be remedied through the medical process: rehabilitation, medication, or other forms of treatment.<sup>20</sup> From this point of view, there is an expectation from society that a person with disabilities will desire and work toward *improving* themselves by seeking to *cure* their disability. The impaired subject is expected to rise to the occasion, bearing the entire burden of overcoming the barriers *inherent to their own existence* in this world, in order to fully access society as any other person would.<sup>21</sup>

This individualistic model can be empowering, but it can also be harmful. It can empower people with disabilities because it gives them the option to improve their own quality of life. For example, a person experiencing chronic pain may be very happy to know that they can access pain-relieving medication or treatment, and this may allow them to fully participate in society. However, the biomedical approach places the responsibility for ensuring participation in society onto disabled people themselves. From this point of view, a disabled person may be expected to compensate for the way the world *is*, even though they took no part in making it the way it is, and had no choice in having an impairment or disability. For example, a blind person could be placed in impossible situations where they are expected to compensate for their inability to see, such as during a written test.<sup>22</sup> The obvious solution in this example is to shift the

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<sup>20</sup> See *ibid* at 15.

<sup>21</sup> See *ibid*.

<sup>22</sup> See Justice Sopinka in Beaudry, *supra* note 19 at 17–18.

responsibility onto the institution administering the test, to expect them to provide an equivalent in braille or through other means.

Another drawback of the biomedical model is one of sheer accessibility: not all people are able to access medical treatment in the same capacity.<sup>23</sup> Medical solutions depend largely on privilege, access, and available resources.<sup>24</sup> Furthermore, the diversity of disabled experiences means that not every disability has a biomedical solution, so some people are completely left behind when this framework is dominant. For example, a person with a clearly defined disability—like diabetes—may function perfectly well in any society so long as they have access to insulin treatment. Someone born with a rare or unknown genetic disorder, however, may not have access to any treatment whatsoever. Evidently, the biomedical framework overlooks social and environmental barriers which contribute to disempowering people with disabilities.

### *The social model of disability*

The second model of disability that I will cover is the social model, which responds to the biomedical model's conception of disability as impairment with the idea that disability is actually engendered by society itself. The social model calls for a distinction to be made between *disability* and *impairment*.<sup>25</sup> Impairment is defined as "[l]acking part or all of a limb, or having a defective limb, organism or mechanism of the body," whereas disability is defined as "the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities."<sup>26</sup> The social model stipulates that society creates barriers when it fails to

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<sup>23</sup> See Amartya Sen, "Human Rights and Capabilities" (2005) 6:2 J of Hum Dev 151 at 153–54.

<sup>24</sup> See generally Harold S Luft, *The New Health Care for Profit: Doctors and Hospitals in a Competitive Environment*, 1st ed (Washington: National Academies Press, 1983).

<sup>25</sup> See Beaudry, *supra* note 19 at 15.

<sup>26</sup> UPIAS, *Fundamental Principles of Disability* (London: Union of Physically Impaired Against Segregation, 1976) at 3–4, cited in Beaudry, *supra* note 19 at 16.

accommodate peoples' impairments, thus making them disabled through means of oppression.<sup>27</sup> From this perspective, a person is only disabled because society has not designed the world to include them, and a shift in social culture toward inclusiveness, rather than oppression, can remedy this. For example, the social model of disability would expect there to be a ramp next to every entrance with stairs to allow people who use wheelchairs to access the entrance. The onus is on society to remove barriers to social participation of people with disabilities, in this case the stairs, because "social obstacles [are what] turn *impaired* persons into *disabled* persons."<sup>28</sup>

The social model also presents some issues. Some people with impairments define themselves as disabled despite not feeling oppressed by society; others find that their impairments alone suffice to characterize them as disabled, despite feeling oppressed by society.<sup>29</sup> In response, some scholars have developed a mixed social model, which recognizes that society can create disability through inaccessibility and oppression, but that it is not the only source of disability.<sup>30</sup>

### *The human rights model of disability*

Another conception of disability lies in the human rights model, which was developed as a framework for the 2006 United Nations' CRPD.<sup>31</sup> The CRPD sought to guide nations to respect the human rights of people with disabilities, and, for that purpose, sought a definition of *disability* from a human rights perspective. This perspective recognizes that impairment and disability are inherent to human diversity, and that these should not be reasons to exclude a person from having the same human rights as anyone else.<sup>32</sup> Thus, the human rights model focuses on accepting rather

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<sup>27</sup> See Beaudry, *supra* note 19 at 15.

<sup>28</sup> *Ibid* at 18.

<sup>29</sup> See *ibid* at 20.

<sup>30</sup> See *ibid* at 20–21.

<sup>31</sup> See CRPD, *supra* note 3, art 12.

<sup>32</sup> See DARU Disability Advocates Resource Unit, "Introducing the human rights model of disability" (2019), online: Disability Advocates Resource Unit

than removing disability, and, much like the social model, expecting society to ascertain the rights of people with disabilities.<sup>33</sup>

The contentious drafting process of the CRPD hinted at the different approaches to disability in various States Parties.<sup>34</sup> Article 12, on the recognition of legal capacity of people with disabilities, was the source of much disagreement and remains so today, as many countries that adopted the CRPD after its publication maintain qualified ratifications that clarify their interpretation of Article 12 in light of their conceptions of disability. These varying conceptions of human rights will be elaborated on in Part III.

Despite—and perhaps in light of—the debate generated by the CRPD, the human rights model remains one of the leading models of disability today. On a concrete level, this model would expect the blind person to access reasonable accommodations during a test; the person with an untreated rare genetic disorder to have the same rights as the person with insulin-managed diabetes; and the person using a ramp to enter a building to never be discriminated against because of their dependence on that ramp.

### *Normative interpretations, societal approaches to disability, and basic assumptions*

As will be discussed in part III, the CRPD's approach to ensuring the respect of the human rights of people with disabilities was hotly debated during drafting, especially regarding the issues of legal capacity and decision-making outlined in Article 12. This disagreement is a testament to how approaches to disability can differ across State Parties' norms and values. These approaches may differ due to the sheer variety of life experiences falling under the umbrella term *disabled*, and how the quality of life of each disabled person is affected by their level of need, their access to

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[www.daru.org.au/how-we-talk-about-disability-matters/introducing-the-human-rights-model-of-disability](http://www.daru.org.au/how-we-talk-about-disability-matters/introducing-the-human-rights-model-of-disability).

<sup>33</sup>See CRPD, *supra* note 3 at preamble.

<sup>34</sup> See Series, *supra* note 3 at 6–8.

resources and support, and their perception in society, among other factors.<sup>35</sup>

These interpretations are not static, and are bound to shift in time, as observed by Foucault in the 1960s. In fact, the shift in approaches to legal capacity of people with disabilities proposed by the CRPD is a testament to progress in the realm of human rights for persons with disabilities on the international stage. The CRPD, whose drafting was done in close collaboration with disability advocates,<sup>36</sup> shows a willingness to progress human rights for persons with disabilities, following in the footsteps of a worldwide reckoning of the rights of other historically oppressed groups, like gender and racial minorities.<sup>37</sup>

In any case, the CRPD denotes a shift in perception of people with disabilities, and pushes the underlying assumption that societies should seek to improve the well-being and quality of life of all of its members, including people with disabilities. Disagreements with the expectations of Article 12 may result from a rejection of this assumption, but they most likely result from a rejection of the approach proposed in the CRPD. Article 12 prescribes a duty to Party States to overhaul how they conceive of disability, how they allocate rights to people with disabilities, and how they structure their decision-making regimes. This may be received as an overly prescriptive approach that doesn't suit the norms and values of every country. This doesn't necessarily mean that countries opposed to the CRPD's approach are against improving the well-being of their own disabled populations. It is possible that many approaches to the complex issue of legal capacity can reach the same end goal of improving the quality of life of people with disabilities.

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<sup>35</sup> For example, see Human Resources and Skills Development Canada, Federal Disability Reference Guide (2013) at 2, online (pdf): Government of Canada <[www.canada.ca/content/dam/esdc-esdc/migration/documents/eng/disability/arc/reference\\_guide.pdf](http://www.canada.ca/content/dam/esdc-esdc/migration/documents/eng/disability/arc/reference_guide.pdf)>.

<sup>36</sup> See Series, *supra* note 3 at 6–8.

<sup>37</sup> This isn't to say that either women or people of colour have achieved ideal human rights, but the U.N. expressly recognized these other groups' equal rights in the UDHR in 1948, while leaving out any mention of people with disabilities (see *Universal Declaration of Human Rights*, GA res 217A (III), UN Doc A/810 71 (1948), art 2).

When thinking transnationally and across cultures, even *improving quality of life* is a vague statement that contains in itself a multitude of definitions.<sup>38</sup> Most people will have different conceptions of what a good life is, and it is unhelpful to be prescriptive when discussing such a broad statement.<sup>39</sup> However, working within the social and human rights models, it could be agreed upon that improving access to society—and thus giving disabled people the choice to participate in political, socio-cultural and economic life—would be considered a good thing by most people in most societies.<sup>40</sup>

Achieving this ambitious goal requires improving access to multiple facets of social life, the most concrete of which is through physical accessibility. Physical access is often the cornerstone of all other types of participation; without representation in physical space, all other forms of representation suffer.

Better physical access to society can be achieved by assessing physical space, through architecture and urban design. These disciplines have the power to mold space, and create or remove real, perceptible barriers. An awareness of this power has led to a reckoning in urban design and architecture for the value of design that centers people. These physical design approaches used in urban planning and architecture can also serve as a basis for approaching more abstract issues outside of the physical realm, such as in designing social and legal policies. In the same way that reframing architecture and urban design can improve physical access to society for people with disabilities by centering their needs, reframing social and legal policies to center people with disabilities can improve their social, political, and economic standing in society, and, hopefully, better support their human rights and improve their quality of life.

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<sup>38</sup> See Committee on the Rights of Persons with Disabilities, *General Comment No. 1 – Article 12: Equal Recognition Before the Law*, April 2014, UN Doc CRPD/C/GC/1, adopted at the 11th Session [*General Comment*].

<sup>39</sup> See Sen, *supra* note 23 at 153–54.

<sup>40</sup> See *General Comment*, *supra* note 38.

## **PART II. The birth of universal design**

### *The power of architecture and urban design*

There is a wealth of literature on the interaction between physical space and human rights. How we shape physical space, for example through architecture, can regulate or control our behaviour.<sup>41</sup> The built environment's effects on behaviour can range from innocuous—such as forcing cars to slow down when a road curves in a residential neighbourhood—to more hostile, possibly nefarious effects—such as excluding certain groups from public spaces.

Architectural design is considered hostile when it intentionally excludes people from community, rather than creating community for all people in a space. A famous example of hostile architecture, or “architectural exclusion,” comes from New York, where infrastructure and architecture have been documented to play a significant role in the health and well-being of its residents.<sup>42</sup> In the 20<sup>th</sup> century, the famous New York builder Robert Moses used architecture to advance a discriminatory agenda. He had designed beautiful public parks by the beaches of Long Island, including Jones Beach. He wanted to keep poor people and people of colour, who mostly lived in the inner city and relied on public transit, away from Jones Beach. Yet, he still wanted richer, white New Yorkers from the city, who had access to cars, to reach the beach. He achieved his goal by purposefully building low-hanging bridges between the inner city and the beaches, under which the tall public buses could not pass.<sup>43</sup>

More recent examples of hostile architecture can be found in cities facing an increase in the number of their homeless

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<sup>41</sup> See Sarah Schindler, “Architectural Exclusion: Discrimination and Segregation Through Physical Design of the Built Environment” (2015) 124 Yale LJ 1934 at 1940.

<sup>42</sup> See generally Deborah Wallace & Roderick Wallace, *A Plague on Your Houses: How New York Was Burned Down and National Public Health Crumbled*, 1st ed (New York: Verso, 1998).

<sup>43</sup> See Schindler, *supra* note 41 at 1937, 1953. See also Langdon Winner, “Do Artifacts Have Politics?” (1980) 109 DAEDALUS 121 at 123–24.

residents.<sup>44</sup> In response to crowding of homeless people in public spaces, some of these cities have redesigned benches and other resting places to discourage loitering or sleeping, to keep homeless people out of the public eye.<sup>45</sup> This example specifically speaks to how public architecture can further political goals, such as satisfying a voter base that does not want to see homelessness on their park benches.<sup>46</sup>

Incidentally, design trends like anti-homelessness benches have a negative effect not only on the vulnerable population they are targeting, but also on other groups. For example, many people with disabilities, chronic illnesses, or who are of old age, rely on the possibility of sitting for a moment's rest when out in public. This is no longer possible when public benches are removed or redesigned to stop people from sitting comfortably.<sup>47</sup> Here, the widespread effect of design on multiple portions of the population is obvious. This effect is the direct result of the moral choices made by policymakers, designers and architects when designing a space.

### *Improving the built environment for people with disabilities*

An increased awareness of the way the built environment can include or exclude certain people from public space has generated discussion in many circles. The groups most often affected by the built environment are minority groups, like people experiencing homelessness, people of colour, and people with disabilities. Despite an increased awareness, changes to the built environment are slow and tricky to instill. Redesigning infrastructure is expensive, and often the policies that allow for

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<sup>44</sup> See, for example, James Petty, "The London Spikes Controversy: Homelessness, Urban Securitisation and the Question of 'Hostile Architecture' " (2016) 5:1 Int J for Crime, Justice & Soc Democracy 67.

<sup>45</sup> See generally Jessica Annan, *An uncomfortable city: a community-based investigation of hostile architecture* (Bachelor of Arts (Honours), University of Victoria, 2015), online <[dspace.library.uvic.ca/handle/1828/13299](https://dspace.library.uvic.ca/handle/1828/13299)> [unpublished].

<sup>46</sup> See Schindler, *supra* note 41 at 1934.

<sup>47</sup> See generally Annan, *supra* note 45.

“architectural exclusion” are hidden away in dusty regulations and confusing municipal policies governing urban design.<sup>48</sup>

Nonetheless, it remains that the built environment is central in our experience of the world and of each other and disability advocates have called for physical representation in public and private spaces. This awareness and campaigning led to the birth of the seven principles of universal design (“the Principles”).<sup>49</sup>

The Principles were conceived in an attempt to create a framework that governments, policymakers, and members of society could follow to integrate universal design into everyday life. They were defined in 1997 by a group of researchers at North Carolina State University. They are the following:

1. Equitable Use
2. Flexibility in Use
3. Simple and Intuitive Use
4. Perceptible Information
5. Tolerance for Error
6. Low Physical Effort
7. Size and Space for Approach and Use.<sup>50</sup>

A set of guidelines accompany each Principle, which clarify the aim of the Principle and help elucidate how to implement it. For example, Principle 3, “Simple and Intuitive Use,” is accompanied by guidelines such as:

- 3a. Eliminate unnecessary complexity;
- 3b. Be consistent with user expectations and intuition;
- 3c. Accommodate a wide range of literacy and language skills.<sup>51</sup>

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<sup>48</sup> See Schindler, *supra* note 41 at 1940.

<sup>49</sup> See Rocky Mountain ADA Centre, “The Evolution of Universal Design: A Win-Win Concept for All” (2020), online: [rockymountainada.org/news/blog/evolution-universal-design-win-win-concept-all](https://rockymountainada.org/news/blog/evolution-universal-design-win-win-concept-all).

<sup>50</sup> See Mace, *supra* note 16.

<sup>51</sup> See *ibid.*

The Principles do not only push architectural and urban design to be more inclusive of people with varying abilities, but also seek to go beyond “accessible design” solutions. Universal design seeks to eliminate the need to *improve* accessibility post-construction by designing inclusively *at the outset*. For example, *accessible design* may deem it acceptable for a building entrance with a staircase to also have a ramp leading to a secondary entrance that could be opened upon request. Though technically accessible, this process for accessing a building is rather cumbersome for the user. *Universal design* would seek to build a step-free entrance that is intuitive and easy for anyone to access.<sup>52</sup>

Of course, the Principles present multiple limitations, the first of which is their idealism. It is difficult to adhere to the Principles without building from scratch; that is why accessible design is more common, especially in older buildings. Of course, the Principles still serve a valuable purpose in guiding new construction when it is possible to adhere to them. Another critique that is made of the Principles is that they are too prescriptive to be completely universal, especially in low income settings where resources are limited, or where they may be conceived as “an imposition of Western values.”<sup>53</sup> Maisel and Ranahan add, when speaking about the cultural limitations of the Principles, that

It is realistic and appropriate to acknowledge that design strategies will differ or be adapted in different places and by different cultures. In some places, achieving the level of accessibility required by Western norms could be counterproductive. Thus, it is important that universal design strategies also address cultural values associated with social, economic, and physical context.<sup>54</sup>

In response, the eight Goals of universal design (“the Goals”) emerged as a complement to the seven Principles. The Goals are less prescriptive than the Principles, though they still remain idealistic. They push us to think about *who* space is being designed for. They emphasize the type of outcome we should seek to achieve through the process of universal design, with an added focus on contextual differences stemming from landscapes,

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<sup>52</sup> This example is from Maisel, *supra* note 15.

<sup>53</sup> *Ibid.*

<sup>54</sup> *Ibid.*

resource limitations, cultural norms, and values. The Goals were introduced by Steinfield and Maisel in 2012 and are summarized as follows:

1. **Body fit.** Accommodating a wide a range of body sizes and abilities;
2. **Comfort.** Keeping demands within desirable limits of body function;
3. **Awareness.** Insuring that critical information for use is easily perceived;
4. **Understanding.** Making methods of operation and use intuitive, clear, and unambiguous;
5. **Wellness.** Contributing to health promotion, avoidance of disease, and prevention of injury;
6. **Social integration.** Treating all groups with dignity and respect;
7. **Personalization.** Incorporating opportunities for choice and the expression of individual preferences;
8. **Cultural appropriateness.** Respecting and reinforcing cultural values and the social, economic and environmental context of any design project.<sup>55</sup>

### *Person-centred design, in architecture and beyond*

The underlying purpose of the Principles and Goals of universal design is to push designers and architects to create person-centred space. Their aim is to guide design of physical spaces that are universally suitable for all users.<sup>56</sup> The Principles and Goals underscore that urban designers and architects make a moral choice when creating space that isn't inclusive. This choice can be deliberate, as it was when Robert Moses designed his low-hanging bridges or when cities create anti-homelessness benches. This choice can also be unintentional, resulting from other considerations, like technical aspects, aesthetics, or resource

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<sup>55</sup> See Steinfield, *supra* note 17.

<sup>56</sup> See Maisel, *supra* note 15.

limitations. As a framework for design, the Principles and Goals seek to make inclusive design a priority where possible.

Furthermore, the Goals of universal design, and their deliberate focus on centering people, can be used to improve more than just physical spaces for people with disabilities. For example, they could be used to make websites or other abstract spaces more accessible. The Goals can be adopted as a framework for policy-making by shaping how those in power think about laws, regulations, and guidelines. Under this framework, policies can be designed in a way that improves the political, economic and socio-cultural life of people with disabilities. In Part III, I will explore how the Goals of universal design may remedy disagreements on decision-making regimes that Party States ought to adopt in light of Article 12 of the CRPD.

### **PART III. Centering people with disabilities in decision-making models**

As discussed in Part I, the diversity of approaches to disability has generated powerful debates between countries, in particular during the drafting of the CRPD in the 2000's. The way in which a society views disability can greatly influence the rights that it grants people with disabilities. Article 12 of the CRPD, in particular, which calls for equal recognition of people with disabilities under the law, was the subject of disagreement during the drafting process and continues to be controversial today.<sup>57</sup>

#### *Shifts in legal capacity for people with disabilities*

Equal recognition of people with disabilities under the law implies that people with disabilities have the same capacity for rights as those who do not have disabilities.<sup>58</sup> The conception of capacity differs between legal traditions. In civil law systems, a distinction is made between the capacity to “have rights and duties” (passive legal capacity) and the capacity to cause rights and duties to arise through [one's] actions with regard to both [oneself] and others” (active legal capacity).<sup>59</sup> In common law traditions, legal capacity is not distinguished in such a way, though the influence of civil law distinctions is clear in the way countries with common law traditions have restricted rights based on legal capacity.<sup>60</sup>

Historically, many vulnerable groups have seen their legal capacity diminished or removed entirely, including women, Indigenous people, people of colour, and poor people.<sup>61</sup>

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<sup>57</sup> See generally Series, *supra* note 3.

<sup>58</sup> See *ibid* at 6.

<sup>59</sup> István Hoffman & György Könczei, “Legal Regulations Relating to the Passive and Active Legal Capacity of Persons with Intellectual and Psychosocial Disabilities in Light of the Convention on the Rights of Persons with Disabilities and the Impending Reform of the Hungarian Civil Code” (2010) 33:1 Loy LA Intl & Comp L Rev 143 at 147.

<sup>60</sup> See *ibid* at 150.

<sup>61</sup> See Renata Bregaglio & Renato Constantino, “Un modelo para armar: la regulación de la capacidad jurídica de las personas con discapacidad en el Perú

Additionally, “disability always implied a restriction of a person’s active legal capacity” because it was assumed that people with disabilities were not able to make rational decisions.<sup>62</sup> In the modern era, however, all people are generally assumed to have passive legal capacity. Certain groups have restricted active legal capacity: children, people temporarily unable to express their will (e.g. due to intoxication) and people permanently unable to express their will (e.g. due to mental illness or intellectual disability).<sup>63</sup> In these cases, the concerned person is generally granted legal representation through a guardian, who exercises some scope of their active legal capacity in their stead, ideally in their best interest.<sup>64</sup> This constitutes a substitute decision-making process in which a person who is deemed incapable of decision-making has someone else make legal decisions for them.<sup>65</sup>

Article 12 of the CRPD represents a departure from the historic treatment of people with disabilities because it not only “reaffirm[s] that persons with disabilities have the right to recognition everywhere as persons before the law” but also calls on states to “recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.” They add that people with disabilities should be given the “support they may require in exercising their legal capacity.”<sup>66</sup> This mention of exercising legal capacity denotes the assumption of Article 12 that people with disabilities not only hold rights (through passive legal capacity), but that they should also exercise them (through active legal capacity), and draws on a supported decision-making framework for them to do so.<sup>67</sup> Article 12 directly contradicts the

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a partir del Decreto Legislativo 1384” (2020) 4 *Revista Latinoamericana en Discapacidad, Sociedad y Derechos Humanos* 32 at 33.

<sup>62</sup> Hoffman & Könczei, *supra* note 59 at 150.

<sup>63</sup> See *ibid* at 151.

<sup>64</sup> See *ibid* at 153.

<sup>65</sup> See Series, *supra* note 3 at 3–4.

<sup>66</sup> CRPD, *supra* note 3, art 12.

<sup>67</sup> See Hoffman & Könczei, *supra* note 59 at 164.

system within many jurisdictions that operate under a substitute decision-making framework, such as Canada.<sup>68</sup>

### *Further clarification on CRPD Article 12*

The controversial nature of Article 12 was not overlooked during the drafting of the CRPD. The drafting of Article 12 occurred over the course of four years between 2002 and 2006, during which eight Ad Hoc Committee sessions took place.<sup>69</sup> During these sessions, interested parties voiced concerns, gave comments and made proposals. Among these parties were the International Disability Caucus (IDC), a collaboration of disability advocates from around the world who gave a representative voice to people with disabilities during the discussions.<sup>70</sup> These organizations formed a working group that drafted an early version of Article 12, in response to which a Canadian proposal was drafted.

The Canadian proposal was submitted and called for an option to “find a person unable to exercise their legal capacity with support” and “provide ... for the appointment of a person representative to exercise legal capacity on the person’s behalf.”<sup>71</sup> This wording allows substitute decision-making, which was expressly rejected in the previous proposals by members of the IDC. The IDC actively opposed substitute decision-making regimes and called instead for “a right to be provided with advocacy assistance” and the abolition of “paternalistic guardianship laws.”<sup>72</sup>

This disagreement led to an explicit discussion on whether or not substitute decision-making regimes should be abolished to

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<sup>68</sup> See Mathieu Dufour, Thomas Hastings & Richard O’Reilly, “Canada Should Retain Its Reservation on the United Nation’s Convention on the Rights of Persons with Disabilities” (2018) 63:12 Canadian Journal of Psychiatry 809 at 810.

<sup>69</sup> See Series, *supra* note 3 at 5.

<sup>70</sup> See *ibid.*

<sup>71</sup> Human Rights of People with Disabilities Ad Hoc Committee, *Article 12 Comments 4th Sess (2005)* online: Comments, proposals and amendments submitted electronically: Canada <[www.un.org/esa/socdev/enable/rights/ahcstata12fscomments.htm#canada](http://www.un.org/esa/socdev/enable/rights/ahcstata12fscomments.htm#canada)>.

<sup>72</sup> Series, *supra* note 3 at 6.

give way to supported decision-making regimes. Many parties that supported the Canadian proposal debated whether substitute decision-making was not simply an extreme, but instead necessary, form of supported decision-making. The IDC responded to these concerns by clarifying the central difference between the two regimes: “the person with a disability is at the center of the discourse.”<sup>73</sup> The IDC also clarified that supported decision-making was a “dynamic concept” that “ranges from zero to 100 per cent.”<sup>74</sup>

The final version of Article 12, published in 2006, remained ambiguous as to whether “legal capacity” of persons with disabilities necessarily meant the capacity to both hold rights and exercise them; and was also unclear on whether or not it prohibited substitute decision-making.<sup>75</sup> This ambiguity led many countries, including “Canada, the Netherlands, Australia, Poland, Egypt, Estonia, Singapore and Norway” to publish clarifications of their interpretations of Article 12 upon ratification of the CRPD.<sup>76</sup> Canada, for example, stated the following:

To the extent Article 12 may be interpreted as requiring the elimination of all substitute decision-making arrangements, Canada reserves the right to continue their use in appropriate circumstances and subject to appropriate and effective safeguards.<sup>77</sup>

In 2014, the UN attempted to elucidate its position on Article 12 of the CRPD by publishing a General Comment. This comment clarifies that “[l]egal capacity includes the capacity to be both a holder of rights and an actor under the law”<sup>78</sup> and that “State parties must ... take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person’s autonomy, will and preferences.”<sup>79</sup> These statements demonstrate that the CRPD firmly stands opposed to substitute decision-making processes and

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<sup>73</sup> *Ibid* at 7.

<sup>74</sup> *Ibid*.

<sup>75</sup> See *ibid* at 8.

<sup>76</sup> *Ibid*.

<sup>77</sup> Dufour, *supra* note 68 at 810.

<sup>78</sup> *General Comment*, *supra* note 38 at para 12.

<sup>79</sup> *Ibid* at para 26.

prioritizes supported decision-making regimes because it finds them to “broaden the decision-making powers of persons with disabilities (in particular, persons with intellectual disabilities) in order to ensure their human dignity, independence, and ability to express opinions.”<sup>80</sup>

### *Changes in legal regimes following of CRPD Article 12*

Some countries with substitute decision-making regimes, like Canada, have yet to shift their positions on the matter, despite calls from disability advocates to do so.<sup>81</sup> These jurisdictions base their position on certain valid reasons, such as the fact that a substitute decision-making process may be safer for individuals who pose a danger to themselves and others, in particular in cases of people with mental illness.<sup>82</sup> In their defense of substitute decision-making, Dufour, Hastings and O’Reilly state the following:

Following the “will and preferences” of the person would prohibit the administration of any treatment that a person did not want, even if the treatment was required to preserve life. This would mean that a person with dementia who was resisting the administration of insulin could not be treated or that a patient with psychosis who is involuntarily hospitalized could not be given antipsychotic medications if he or she refused.<sup>83</sup>

In addition, some find that the current Canadian scheme has “generally served patients and their families well” and that the federal government should therefore maintain its reservations to Article 12 until more concrete research is completed on procedures to follow in a supported decision-making scheme in difficult cases.<sup>84</sup> There is substantial hesitancy on the basis that countries aren’t sure how to proceed in difficult situations without a substitute decision-making framework.

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<sup>80</sup> Hoffman & Könczei, *supra* note 59 at 164.

<sup>81</sup> See Dufour, *supra* note 68 at 810.

<sup>82</sup> See *ibid* at 811.

<sup>83</sup> *Ibid*.

<sup>84</sup> *Ibid*.

Policymakers defending supported decision-making regimes reaffirm that it is a flexible scheme that varies on a case-by-case basis. Indeed, there are obvious situations in which a person is unable to express a will and no advance directives or personal wishes exist. For instance, if someone is born with a severe intellectual disability, any form of supported decision-making for them would in fact be a substitute decision-making scheme. However, supported decision-making regimes in general would allow for more thorough investigation into the wishes and desires of a person not completely able to express a will, as is sometimes the case for people with disabilities.<sup>85</sup> This investigative process is arguably more arduous than the decision to hand off decision-making to a substitute representative, but it squarely centers the person with disabilities within discussions. There is no blanket declaration of incapacity under supported decision-making regimes, but, rather, the presumption of capacity, that in some cases may be almost null.<sup>86</sup> This always keeps the person with disabilities at the centre of the discourse, with their capacity being the chief concern. If ever they were able to express a will, then respecting it is a priority under a supported decision-making framework.

Some countries have shifted their decision-making regimes in response to the CRPD and the General Comments. Peru, for example, along with other South American countries, overhauled its Civil Code in 2018. Peruvian lawmakers included provisions for recognition of legal capacity of people with disabilities and a supported decision-making regime (a system of *apoyos*), in a clear chasm from the previous guardianship regime (a system of *interdicción*).<sup>87</sup> The reform calls for people with disabilities to have the choice to call on help from an *apoyo* whenever they feel that they need help through a notarial or judicial process; they are also the one to determine from whom they receive support, to what extent, for how long, and for what types of decisions.<sup>88</sup> *Apoyos* are tasked with facilitating three main tasks:

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<sup>85</sup> See generally Piers Gooding, “Supported decision-making: a rights-based disability concept and its implications for mental health law” (2013) 20:3 *Psychiatry, Psychology and Law* 431.

<sup>86</sup> See *ibid.*

<sup>87</sup> See Bregaglio, *supra* note 61 at 34.

<sup>88</sup> See *ibid* at 47.

communication to accomplish legal acts, understanding of legal acts and their consequences, and facilitating manifestation of wills for people who call on them.<sup>89</sup> A series of safeguards (*salvaguardias*) are also determined when *apoyos* are named or requested to allow for oversight and prevent abuses of power.<sup>90</sup> As the new regime has been implemented, legal experts have observed how the system deals with complex cases, like those where a person's will is hard to ascertain, or where their rights, wishes and best interests are in conflict.<sup>91</sup>

There are also *exceptional apoyos* that can be determined by judges for people with disabilities in the first case, where it is impossible to determine the person's will.<sup>92</sup> This determination is subject to verification that all means of communication with the person have been exhausted, and is granted to people close to the person, such as friends, family or caretakers.<sup>93</sup> It is a step that can only be taken if it is necessary for the protection or exercise of the concerned persons' rights, and only extends to decisions regarding rights needing protection.<sup>94</sup> Of course, *exceptional apoyos* have all the characteristics of a substitute decision-maker; yet, Peruvian academics Bregaglio and Constantino defend their necessity in certain extreme cases:

To ignore these cases at a regulatory level would lead to a lack of protection of these people, who would neither be able to request an *apoyo* nor defend their own rights without one, because they are unable to express their will.<sup>95</sup>

*Apoyos* are also expected to invest some time and effort in ascertaining that an expressed desire is truly voluntary. For example, a person with Alzheimer's disease may sometimes express a will to sell their home, but, at other times, wish the

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<sup>89</sup> See *ibid* at 49.

<sup>90</sup> See *ibid* at 53, 55.

<sup>91</sup> See *ibid* at 43.

<sup>92</sup> See *ibid* at 51, 53.

<sup>93</sup> See *ibid* at 52.

<sup>94</sup> See *ibid*.

<sup>95</sup> *Ibid* at 53.

opposite.<sup>96</sup> These difficult situations are dealt with on a case-by-case basis. The *apoyo*'s evaluation will largely depend on how clearly the expression of will is made over time. Decisions like these are subjected to safeguards which ensure that a person's expressions aren't made under *undue influence*, and that they are not being taken advantage of.<sup>97</sup>

Despite safeguards and clear guidelines on how to implement supported decision-making, these regimes still have drawbacks. In practice, resource limitations could mean that people under exceptional guardianships are not safeguarded as well as they should be, which still leaves open the option for abuse by *apoyos*.

Further, *apoyos* are named for specific legal actions and hold restricted roles. These roles are supervised through regular review of cases by the courts. This is an exhaustive process that could strain legal systems that are already overburdened in most countries.<sup>98</sup> Finally, the process required to expand an *apoyo*'s role if circumstances change could be burdensome to both the person with disabilities and the *apoyo*. However, *apoyos* risk legal sanctions if they go beyond their stated powers without being allowed to do so, following a formal request by the person with disabilities or a judicial ruling.

From a human rights perspective, all regimes should seek to respect the rights, dignity, and well-being of people. The CRPD's Committee concluded that the best way to do this was through a supported decision-making regime. This type of regime allows for the most flexibility—including 100% support in necessary cases—when helping people with disabilities exercise their legal rights. Yet, the CRPD's mandate is prescriptive, and we should consider that its implementation is not necessarily realistic, pragmatic, or beneficial in all contexts. It enforces a moral choice, albeit one that centers people with disabilities and that has been voiced as preferential by most groups representing disabled people. Laws are put in place to reflect the values and morals touted by a

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<sup>96</sup> See *ibid.*

<sup>97</sup> See *ibid* at 54.

<sup>98</sup> See generally United Nations Office of Drugs and Crime, *Global Study on Legal Aid Global Report* (2016) at 5, online: UNODC <[www.unodc.org/documents/justice-and-prison-reform/LegalAid/Global-Study-on-Legal-Aid\\_Report01.pdf](http://www.unodc.org/documents/justice-and-prison-reform/LegalAid/Global-Study-on-Legal-Aid_Report01.pdf)>.

society.<sup>99</sup> To change laws requires a shift in the underlying morals and values.

As such, the multiple qualified ratifications of Article 12 come as no surprise. Canada, for example, rejected the call for supported decision-making and continues to defend substitute decision-making as a moral choice that prioritizes the protection of vulnerable groups over their autonomy. Canada prefers to err on the side of overprotection of this vulnerable population, to the detriment of their autonomy. Of course, this assumes that people with disabilities would not make rational decisions if granted full autonomy, and follows older conceptions of people with disabilities. It also reinforces stereotypes about people with disabilities by pushing the narrative that they cannot make decisions themselves. Other countries qualified their ratifications on the basis of interpreting specific wording relating to legal capacity in Article 12.<sup>100</sup>

### *Adopting universal design to promote pragmatic policy-making*

I now turn to the concepts included in the Goals of universal design, especially the following:

- “Accommodating a wide range of ... abilities;”
- “Keeping demands within desirable limits;”
- “Awareness;”
- “Understanding;”
- “Contributing to health promotion;”
- “Social integration” and “treating all groups with dignity and respect;”
- “Incorporating opportunities for choice and the expansion of individual preferences;”

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<sup>99</sup> See generally Eric Posner, *Law and Social Norms*, revised ed (Boston: Harvard University Press, 2012).

<sup>100</sup> See, for example, Bregaglio, *supra* note 61 at 36-38.

- and “cultural appropriateness.”<sup>101</sup>

From these concepts, the aim of the Goals is clear: they seek to value people as the most important consideration within design. Not only do they seek to center the person in designs, but they also seek to improve their quality of life. I propose that these concepts be used to assess how to best design decision-making regimes across societies to best serve people with disabilities.

Of course, the supported decision-making framework was designed in alignment with the human rights conception of disability, which also centers people with disabilities. Therefore, the supported decision-making framework aligns well with the universal design Goals set out by Maisel et al. However, it may be too harsh to write off substitute decision-making regimes altogether in all cultural contexts. We must give proper regard to resource limitations, the success of regimes already in place, the complications of redesigning a system, and the issues of accessibility that may arise.

It may be more realistic to apply the Goals of universal design to substitute decision-making regimes. This may allow for policies that shape these substitute decision-making regimes to consciously center the person with disabilities. This may be achieved by implementing more rigorous safeguards over time, doing away with guardianship regimes that have no possibility of being terminated, and eventually the recognition of active legal capacity on a zero to 100 scale.<sup>102</sup> Of course, over time, these would become supported decision-making regimes under another name.

Pushing for countries to adopt a system that is too prescriptive in nature, especially if guidelines for its function and implementation aren't clear at the outset, could lead to conflict. Enforcing supported decision-making regimes without due consideration for their implementation could lead to a lack of regulatory oversight and the temporary or permanent abandonment of certain people with disabilities, like those particularly vulnerable groups mentioned by Dufour et al and by

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<sup>101</sup> Steinfeld, *supra* note 17.

<sup>102</sup> See, for example, Ronan Farrow & Jia Tolento, “Britney Spears’ Conservatorship Nightmare”, *The New Yorker* (2021), online: [www.newyorker.com/news/american-chronicles/britney-spears-conservatorship-nightmare](https://www.newyorker.com/news/american-chronicles/britney-spears-conservatorship-nightmare).

Bregaglio and Constantino.<sup>103</sup> To change the mandate of Party States from overhauling a regime to shifting its focus to centering people with disabilities may be more accessible in States with less resources, with more strained legal systems, or who are very reticent about moving away from current systems. In any case, this process may help guide countries that still maintain their position on substitute decision-making toward a more person-centred approach, and, eventually, a supported decision-making system that best champions the human rights of people with disabilities. This process would also give societies a guide to reassessing their own views and biases about people with disabilities, to shift their conceptions firmly into the human rights model of disability, so that a fully supported decision-making regime can be respected and successful when it is implemented.

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<sup>103</sup> See Dufour, *supra* note 68 at 811; Bregaglio, *supra* note 61 at 53.

## Conclusion

Conceptions of disability frame how we choose to address issues like decision-making in the field of disability law. These conceptions will continue to shift over time, following political and social climates. The current human rights framework is person-centred. It focuses on advocating for the dignity and autonomy of this vulnerable group. I am hopeful that this framework will, over time, become dominant in most societies. Normative changes in other disciplines, like architecture, justify my hope. I look to universal design and its incremental integration into the infrastructure of cities as a sign of societies' willingness to better integrate people with disabilities into social, economic, and political life.

The various cultural differences in societies make it difficult to impose drastic changes on a transnational level, even if the international community is able to come to an agreement. From the debate on decision-making, I believe a lot of the issues stem from a lack of guidance on how to best integrate their recommendations on a granular level. Adopting the goals of universal design in policy-making may help remedy this opacity.

When I think about the young man with Down's Syndrome whom I helped assist at the IDEHPUCP clinic, I think about the work that led to our decision to name his mother as an *apoyo*. Generations of disability rights advocates petitioned in order for this young man to have the opportunity to choose who can help him and in what capacity. The final decision at which we arrived was for his mother to proceed with the requests process in his stead. On its face, this decision was analogous to the one that would have been made under a substitute decision-making framework. However, his voice wouldn't have been heard in the previous regime. He would have had no power to limit his mother's role in his financial affairs. He would have been more vulnerable to abuse.

Perhaps, his life would not be substantially different in either regime. However, there is something to be said about the freedom he now has in choosing how, when and to what extent others can take charge of his legal affairs. The value of his freedom to choose cannot be understated, and my hope is that better implementation of supported decision-making frameworks can allow for these

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types of frameworks to flourish, following recommendations of disability advocates and the CRPD.

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