

# Meaningful Participation of Persons with Disabilities in Regulating Making

### Final Report

March 31, 2021

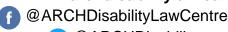
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# The *Accessible Canada Act*: An Opportunity to Create More Meaningful and Inclusive Processes for Persons with Disabilities to Participate in Making Regulations

On July 11, 2019, the *Accessible Canada Act* (*ACA*),<sup>1</sup> the first federal accessibility legislation in Canada, was proclaimed into force. The purpose of the *ACA* is to achieve a barrier-free Canada by 2040. To accomplish this goal, the *ACA* creates a framework for removal and prevention of barriers to accessibility in specific areas of federal jurisdiction, including: employment; the built environment; information and communication technologies; communication; the procurement of goods, services and facilities; and the design and delivery of programs and services.<sup>2</sup> Additional areas can be designated by regulations.<sup>3</sup>

The ACA grants powers to the Government of Canada, the Canadian Transportation Agency, and the Canadian Radio-television and Telecommunications Commission to enact new regulations. These regulations will impose accessibility planning and reporting requirements and substantive accessibility requirements upon regulated entities designated by the ACA. New regulations to enforce these accessibility requirements will also be enacted, such as administrative monetary penalties for regulated entities who fail to comply.

The creation of these new accessibility regulations presents a rare opportunity to examine existing federal processes by which persons with disabilities participate in the development of regulations that affect them, and to seek to create processes that are more meaningful and inclusive. The inclusion of persons with disabilities in accessibility regulation-making processes is essential to ensuring that these regulations address the barriers they experience, and achieve the intended purpose of the *ACA*. To truly make Canada more accessible, accessibility regulations must be developed with meaningful participation and involvement of persons with disabilities.

This Final Report is structured in eight parts. First, we discuss the objectives of the Meaningful Participation of Persons with Disabilities in Regulation Making Project, including how this project was conceived and why its goals are important. Second, we describe the substantive equality and rights-based approach taken throughout this project. Third, we describe the methods used in the legal research, empirical research, and work with our five disability community project partners that formed the basis for our

<sup>&</sup>lt;sup>1</sup> Accessible Canada Act, SC 2019, c 10 [ACA]

<sup>&</sup>lt;sup>2</sup> *Ibid.* s 5

<sup>&</sup>lt;sup>3</sup> *Ibid*, s 117(1)(b)

results and recommendations. Fourth, we outline the results of the research, focusing on barriers in regulation making processes and potential solutions. Fifth, we outline how our project relates to other projects about accessible regulation making, including work done by the ESDC Innovation Lab regarding guidance documents. Sixth, we outline our recommendations and connect them to our research findings. Seventh, we discuss avenues for further research that may extend the findings of our project. Finally, we provide a conclusion that summarizes the themes and recommendations advanced in this Final Report.

### Part I: Project Objectives

### Project Rationale and Goals

This project was conceived in the early stages of accessibility regulation development under the *ACA*. The Government of Canada wanted to promote meaningful participation of persons with disabilities in the development of these accessibility regulations. The Government wanted persons with disabilities to understand and take interest in regulation making so that it could receive feedback reflecting the perspective of disability communities. Given the opportunities presented by the enactment of the *ACA* and its regulations, the rationale for this project was to enable and facilitate more meaningful participation of persons with disabilities in the development of new *ACA* regulations.

To achieve this rationale, we identified the following project goals:

- identify barriers within existing federal regulatory development processes that impact persons with disabilities;
- develop recommendations for regulators, aimed at removing those barriers and creating more accessible regulatory development processes; and
- build capacity within disability communities to participate in existing federal regulatory development processes.

The goals of this project are important for achieving the aspirations of the *ACA*. The Government of Canada intended the *ACA* to promote the inclusion of persons with disabilities as much as possible. Carla Qualtrough, then Minister of Public Services and Procurement and Accessibility, explained that the goal of this legislation is "building a Canada without barriers, where people with disabilities participate fully and equally in

their communities".<sup>4</sup> The project goals are also important for fulfilling the legislative requirements in the *ACA*. Section 6(f) of the *ACA* states that "persons with disabilities must be involved in the development and design of laws, policies, programs, services and structures."<sup>5</sup> Other principles of the *ACA* provide guidance regarding what "involvement" may mean, highlighting the importance of the diversity of communities of persons with disabilities, the promotion of their dignity, and the achievement of "the highest level of accessibility",<sup>6</sup> as we describe in more detail later on.

This project also aims to further full and effective participation of persons with disabilities in society, as outlined in the United Nations *Convention on the Rights of Persons with Disabilities (CRPD).*<sup>7</sup> Meaningful participation allows persons with disabilities to frame policy issues, to challenge discriminatory and inaccurate assumptions, and to develop an empowering relationship with the law.<sup>8</sup> It also facilitates capacity building to support advocacy about and expression of living experiences.<sup>9</sup>

In contrast, when regulatory development is not meaningful, persons with disabilities are left with no choice but to challenge the resulting regulations through political advocacy, the media, and legal challenges. <sup>10</sup> Even if positive changes are eventually won or negotiated, the resources required and delay incurred can have significant consequences for persons with disabilities, other stakeholders, and regulators. As well, this adversarial approach undermines efforts to establish positive practices of mutual information sharing to ensure better regulations from the outset.

While the development of *ACA* regulations should include accessible processes for the participation of persons with disabilities, it is important to note that <u>all</u> legislation and regulation-making processes should be accessible. Lawmaking in a myriad of areas may implicate the interests of persons with disabilities in diverse and unexpected ways. Although our recommendations focus on *ACA*-related regulation development

<sup>7</sup> Convention on the Rights of Persons with Disabilities, 13 December 2006, 2515 UNTS 3 (entered into force 3 May 2008, Convention ratified by Canada on 11 March 2010, Optional Protocol ratified by Canada on 3 December 2018) art 3 [CRPD]

<sup>&</sup>lt;sup>4</sup> Bill C-81, "An Act to ensure a barrier-free Canada", 3rd reading, *House of Commons Debates*, 42-1, No 355 (21 November 2018) at 1530 (Hon Carla Qualtrough)

<sup>&</sup>lt;sup>5</sup> ACA, above, s 6(f)

<sup>&</sup>lt;sup>6</sup> *Ibid*, s 6(g)

<sup>&</sup>lt;sup>8</sup> Laufey Löve *et al*, "The Inclusion of the Lived Experience of Disability in Policymaking" (2017) 33:6 Laws 1 at 3; Laufey Löve, Rannveig Traustadóttir & James Gordon Rice, "Achieving Disability Equality: Empowering Disabled People to Take the Lead" (2017), 6:1 Social Inclusion 1 at 6

<sup>&</sup>lt;sup>9</sup> United Nations Committee on the Rights of Persons with Disabilities, "General comment No 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention," 9 November 2018, CRPD/C/GC/7 at para 19, available online:

https://tbinternet.ohchr.org/\_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/7&Lang=en [General Comment No 7]

<sup>&</sup>lt;sup>10</sup> Löve, Traustadóttir & Rice, above at 5-6; David Lepofsky & Randal Graham, "Universal Design in Legislation: Eliminating Barriers for People with Disabilities" (2009), 30:2 Statute Law Review 129 at 157

processes, the best practices identified in this project are significant for the development of all legislation and regulations.

### **Disability Community Project Partners**

At each stage, this project has been informed and supported by the input and living experiences of persons with disabilities. ARCH undertook this work in collaboration with five disability community project partners: Canadian Association of the Deaf, Council of Canadians with Disabilities, Communication Disabilities Access Canada, National Coalition of People Who Use Guide and Service Dogs in Canada, and People First of Canada. Our project partners provided feedback, recommendations and support that informed all aspects of our research, analysis and final recommendations. ARCH thanks our project partners for their extensive contributions to this project. ARCH acknowledges that the project partner organizations are not representative of all of the diverse perspectives within communities of persons with disabilities.

### Part II: Methods

We used multiple methods to achieve the project's goals of identifying barriers within existing federal regulatory development processes that impact persons with disabilities; developing recommendations for regulators, aimed at removing those barriers; creating supports that promote participation; and creating more accessible regulatory development processes. ARCH completed extensive legal research, including identifying and analyzing academic scholarship, case law, international law sources, and independent reviews of standards development processes conducted at the provincial level. ARCH conducted an empirical study in partnership with researchers at McGill University to collect data through interviews with persons with disabilities. In addition, throughout the project we worked with our disability community project partners to understand their experiences with regulation development processes.

### Legal Research

Our legal research was conducted from a substantive equality perspective for the reasons described above. Consequently, we reviewed case law relating to substantive equality and the participation of persons with disabilities in regulation and legislative development; the *CRPD* and General Comments authored by the UN Committee on the

<sup>&</sup>lt;sup>11</sup> Osgoode Hall Law School at York University was also a partner in the Meaningful Participation of Persons with Disabilities in Regulation Making Project.

Rights of Persons with Disabilities; and academic scholarship relating to participation of persons with disabilities in regulation and policy making. We thank Osgoode Hall Law School at York University for providing helpful feedback on our analysis of this legal research. This work yielded several principles relating to accessible and inclusive regulation development that are consistent with the section 6 principles in the *ACA*. We have used these section 6 principles to structure our analysis of all of our results, outlined below.

As well, we analyzed barriers documented in the independent reviews of accessibility legislation in Ontario and Manitoba. In Ontario, standards committees developed and proposed accessibility standards regulations under the *Accessibility for Ontarians with Disabilities Act, 2005.*<sup>12</sup> Each committee included persons with disabilities or their representatives. Although this model was seen as innovative at the time, it encountered significant challenges. Similarly, Manitoba has enacted two accessibility standards under *The Accessibility for Manitobans Act.*<sup>13</sup> Under this legislation, an Accessibility Advisory Council comprised of persons with disabilities and others develops standards based on the Minister's terms of reference or provides a draft standard to a standards development committee for analysis.<sup>14</sup>

Finally, we conducted research on existing federal processes to develop regulations used by the Government of Canada, the Canadian Transportation Agency and the Canadian Radio-television and Telecommunications Commission (CRTC). We met with staff from the Accessibility Secretariat, the Canadian Transportation Agency, and the CRTC to learn about their processes and opportunities for persons with disabilities to participate. We discussed some of the barriers and concerns that were revealed in our early legal research and work with the project partners. This allowed us to better understand the perspectives that government and regulators bring to regulation making, how they perceive the process and feedback from persons with disabilities, and potential opportunities for reform.

### Qualitative Study in Partnership with McGill University

ARCH partnered with a research team at McGill University to conduct empirical research. This team was led by Dr. Keiko Shikako-Thomas, Canada Research Chair in Childhood Disabilities: Participation and Knowledge Translation and Associate Professor, School of Physical and Occupational Therapy, and Dr. Mehrnoosh Movahed, Research Associate,

<sup>&</sup>lt;sup>12</sup> Accessibility for Ontarians with Disabilities Act, 2005, SO 2005, c 11 [AODA]

<sup>&</sup>lt;sup>13</sup> The Accessibility for Manitobans Act, CCSM c A1.7

<sup>&</sup>lt;sup>14</sup> Theresa Pruden, "Independent Report on the Effectiveness of the Implementation of The Accessibility for Manitobans Act" (December 2018) at 15, online: <a href="http://www.accessibilitymb.ca/pdf/ama-review.pdf">http://www.accessibilitymb.ca/pdf/ama-review.pdf</a>

School of Physical and Occupational Therapy. The study was approved by the Research Ethics Board of McGill University. 15

The McGill research team conducted semi-structured interviews with 36 participants.<sup>16</sup> These participants were chosen using a maximum variation sampling strategy, meant to include people who belong to diverse disability groups who had participated in the development of laws, regulations, standards and policies relating to disability.<sup>17</sup>

22 of these participants identified as having a disability.<sup>18</sup> They included persons with sensory disabilities (defined by the researchers as blind, deaf, or deaf-blind), motor and physical disabilities, mental health disabilities and cognitive/learning disabilities.<sup>19</sup> For further demographic information relating to the participants, go to Appendix I, McGill University's "Meaningful Participation in Regulation Making" Report at page 7.

The interviews took about 1-2 hours each.<sup>20</sup> The interview questions were framed around barriers that prevent meaningful participation in regulation making processes and facilitators that promote participation.<sup>21</sup>

The researchers then analyzed the results of the interviews using NVivo 12, a qualitative data management computer software.<sup>22</sup> They applied an interpretative descriptive analysis methodology that allowed them to analyze and describe the living experience of the participants.<sup>23</sup>

### Work with Disability Community Project Partners

ARCH's disability community project partners were the Canadian Association of the Deaf, the Council of Canadians with Disabilities, Communication Disabilities Access Canada, the National Coalition of People Who Use Guide and Service Dogs in Canada, and People First of Canada.

Over the course of this project, we met with our project partners regularly regarding the research findings and their experiences participating in regulation development

<sup>&</sup>lt;sup>15</sup> Movahed, M., Gonzalez, M., Sogomonian, T., Chowdhury, F., & Shikako-Thomas, K, "Meaningful participation in regulation making" (October 2020), report submitted to ARCH Disability Law Centre at 6

<sup>16</sup> *Ibid* at 7

<sup>&</sup>lt;sup>17</sup> *Ibid* at 5

<sup>18</sup> *Ibid* at 7

<sup>19</sup> Ibid

<sup>20</sup> Ibid at 6

<sup>&</sup>lt;sup>21</sup> Ibid

<sup>&</sup>lt;sup>22</sup> Ibid

<sup>&</sup>lt;sup>23</sup> Ibid

processes. We developed our recommendations in collaboration with our project partners.

ARCH and our project partners worked together to participate in several regulatory development processes under the ACA, including consultations held by the Canadian Transportation Agency regarding the Accessible Transportation for Persons with Disabilities Regulation and guidelines on accessible transportation for medium and small transportation providers; a consultation held by the CRTC regarding the structure of accessibility regulations for broadcasting and telecommunications providers; and consultations held by the Accessibility Secretariat regarding the ACA Technical Regulations. For each of these consultations we held working meetings with our project partners. These collaborative meetings allowed ARCH to support the project partners in their development of written submissions. In turn, they also informed ARCH's own written submissions. During these working meetings, our project partners identified barriers they were experiencing in the regulation making process, as well as potential solutions. They reflected on their previous experiences with regulatory development, as well as with the development of ACA regulations in particular. This work was invaluable in helping to shape our understanding of barriers within these processes, and our recommendations for making these processes more accessible and inclusive. Projects that evaluate the participation of persons with disabilities in policymaking may be conducted with the involvement of community members to reflect their living experience in the project design and implementation.<sup>24</sup>

In addition to participating in regulatory development processes, we also worked with our project partners to participate in a consultation held by Accessibility Standards Canada regarding priorities for the development of *ACA* accessibility standards.

Finally, our project partners provided extensive time, input and services to co-create with ARCH educational resources about *ACA* regulation making. These educational resources are aimed at supporting people with disabilities to participate more effectively in the development of federal accessibility regulations. They will be made publicly available in multiple accessible formats and in English, French, American Sign Language, langue des signes Québécoise, English captioning and French captioning. While this Final Report is not written in plain language, the educational materials have been co-developed in plain language, and designed to be as universally accessible as possible.

Implementation" (2010) 9:2 Social Policy & Society 207

<sup>&</sup>lt;sup>24</sup> For another example, go to Karen Fisher & Sally Robinson, "Will Policy Makers Hear My Disability Experience? How Participatory Research Contributes to Managing Interest Conflict in Policy

## Part III: A Substantive Equality Approach Informed by the Convention on the Rights of Persons with Disabilities

ARCH used a substantive equality approach as our analytical framework for this project. Below we discuss the key concepts inherent in this framework and their sources. In Part IV and V of this report we explain how we applied this framework to our findings and recommendations.

### A Rights-Based Approach to Regulation Making

A rights-based approach grounded in substantive equality is crucial to an analysis of how to accessibly and meaningfully include persons with disabilities in regulation making. A rights-based approach recognizes the pervasive discrimination and inequality that persons with disabilities experience. It recognizes that persons with disabilities are legally entitled, by virtue of the *Charter*, human rights law, and Canada's ratification of the *CRPD*, to equal access to goods, services, employment and other areas of life, and to participate on an equal basis as others in the development of laws and regulations that affect them.

The preamble to the *ACA* recognizes that this legislation is intended to further the "economic, social and civic participation of all persons in Canada, regardless of their disabilities", complementing the rights of persons with disabilities articulated in both domestic and international law.<sup>25</sup> The preamble specifically refers to concepts of substantive equality recognized under the *Canadian Human Rights Act*<sup>26</sup> and the *Canadian Charter of Rights and Freedoms*.<sup>27</sup> In addition, the preamble acknowledges that the *ACA* plays a crucial role in implementing parts of the *CRPD* "to take appropriate measures respecting accessibility and to develop and monitor minimum accessibility standards."<sup>28</sup> Given the strong, complementary relationship between the *ACA* and domestic and international human rights laws, it is fitting that our analysis is conducted from a human rights-based perspective.

The Supreme Court of Canada has recognized the multitude of experiences of persons with disabilities, commenting on their "widely divergent needs, characteristics and circumstances."<sup>29</sup> The Court explained that "[d]ue sensitivity to these differences is the

<sup>26</sup> Canadian Human Rights Act, RSC 1985, c H-6 [CHRA]

<sup>&</sup>lt;sup>25</sup> ACA, above, preamble

<sup>&</sup>lt;sup>27</sup> Canadian Charter of Rights and Freedoms, s 15, Part I of the Constitution Act, 1982, being Schedule B to the Canada Act 1982 (UK), 1982, c 11 [Charter]

<sup>&</sup>lt;sup>28</sup> ACA, above, preamble

<sup>&</sup>lt;sup>29</sup> Nova Scotia (Worker's Compensation Board) v Martin; Nova Scotia (Worker's Compensation Board) v Laseur, 2003 SCC 54, [2003] 2 SCR 504 at para 81 [Martin]

key to achieving substantive equality for persons with disabilities."<sup>30</sup> Consequently, a substantive equality analysis requires an appreciation of the actual capacities and circumstances of persons with disabilities.<sup>31</sup> The Court has also recognized that "the history of disabled persons in Canada is largely one of exclusion and marginalization", and that persons with disabilities have been "subjected to invidious stereotyping and relegated to institutions".<sup>32</sup> Counteracting harmful stereotypes is critical to addressing the historical and present-day discrimination experienced by persons with disabilities.

Substantive equality for persons with disabilities has been described in Canadian law as "full membership in Canadian society."<sup>33</sup> It is informed by the fundamental concept of dignity, which the Supreme Court of Canada has recognized as "an essential value underlying the s. 15 equality guarantee".<sup>34</sup>

For example, in *Eldridge*, the Supreme Court required British Columbia to provide sign language interpretation in hospital emergency wards to ensure that Deaf persons had equal access to health care services. Justice La Forest quoted Justice Sopinka's statement in *Eaton v Brant County Board of Education*<sup>35</sup> to explain what substantive equality requires for persons with disabilities:

Exclusion from the mainstream of society results from the construction of a society based solely on "mainstream" attributes to which disabled persons will never be able to gain access [...] it is the failure to make reasonable accommodation, to fine-tune society so that its structures and assumptions do not result in the relegation and banishment of disabled persons from participation, which results in discrimination against them.<sup>36</sup>

The Law Commission of Ontario (LCO) has described substantive equality in a similar manner, stating that persons with disabilities should have "concrete opportunities to participate, have needs taken into account and have society and its structures and organizations develop in a way that does not treat persons with disabilities as outside mainstream society".<sup>37</sup> Explained another way, persons with disabilities "are not defined"

<sup>31</sup> Granovsky v Canada (Minister of Employment and Immigration), 2000 SCC 28 at para 27, [2000] 1 SCR 703

<sup>30</sup> Ibid

<sup>&</sup>lt;sup>32</sup> Eldridge v British Columbia (Attorney General), [1997] 3 SCR 624 at para 56 [Eldridge]

<sup>33</sup> Quebec v A, 2013 SCC 5 at para 200

<sup>&</sup>lt;sup>34</sup> R v Kapp, 2008 SCC 41 at para 21 [Kapp]

<sup>&</sup>lt;sup>35</sup> Eaton v Brant County Board of Education, [1997] 1 SCR 241 [Eaton]

<sup>&</sup>lt;sup>36</sup> Eldridge, above at para 65 quoting Eaton, above at para 67

<sup>&</sup>lt;sup>37</sup> Law Commission of Ontario, "The Framework for the Law as It Affects Persons with Disabilities: Advancing Substantive Equality for Persons with Disabilities through Law, Policy and Practice" (Toronto, Canada: 2012), Chapter IV at 65, available online: <a href="https://www.lco-cdo.org/wp-content/uploads/2012/12/persons-disabilities-final-report.pdf">https://www.lco-cdo.org/wp-content/uploads/2012/12/persons-disabilities-final-report.pdf</a>

by the barriers they face, but are recognized as members of society who are able to make contributions and have obligations, as do other members". 38

Substantive equality also accounts for the intersectional experiences of persons with disabilities. Carol Aylward defines intersectional rights claims as equality claims based on multiple sites of discrimination that are "distinct" from discrimination faced by any of the individual grounds alone:

[i]ntersectionality has been described as the ability of Black women, Aboriginal women, other women of colour, women with disabilities, lesbian women, or poor women, to base a claim of discrimination under s.15 of the *Charter* as a distinct group of women who are subject to a form of discrimination quite apart from that experienced (in the case of Black women) by Black men and White (and other women) regardless of colour. The form of discrimination experienced by Black women is not related to some "immutable" characteristic(s) inherent in Black women (skin colour for example), but rather, it is a form of discrimination arising because of society's stereotyping of Black women and its historical treatment of them.<sup>39</sup>

Aylward explains that intersectional rights claims may be based on one or more enumerated or analogous grounds under *Charter* section 15, and the distinct intersectional claim is itself an analogous ground.<sup>40</sup> Consistent with Aylward's analysis, the Supreme Court of Canada has recognized that *Charter* claims under the equality guarantee may be pursued based on "an intersection of grounds".<sup>41</sup>

Substantive equality is also reflected in key elements of the *ACA*. The *ACA* defines disability as:

any impairment, including a physical, mental, intellectual, cognitive, learning, communication or sensory impairment — or a functional limitation — whether permanent, temporary or episodic in nature, or evident or not, that, in interaction with a barrier, hinders a person's full and equal participation in society.<sup>42</sup>

<sup>38</sup> Ibid

<sup>&</sup>lt;sup>39</sup> Carol Aylward, "Intersectionality: Crossing the Theoretical and the Praxis Divide" (2010) 1:1 Journal of Critical Race Inquiry 1 at 16-17

<sup>40</sup> Ibid at 17

<sup>&</sup>lt;sup>41</sup> Law v Canada, [1999] 2 SCR 203 at 554-555. See also: Corbiére v Canada, [1999] 2 SCR 203 where Justice L'Heureux-Dubé stated, in her concurrence, that an equality analysis should account for "stereotyping, prejudice, or denials of human dignity and worth that might occur in specific ways for specific groups of people, to recognize that personal characteristics may overlap or intersect (such as race, band membership, and place of residence in this case), and to reflect changing social phenomena or new or different forms of stereotyping or prejudice" (para 61).

This definition was intended to be broad and inclusive, consistent with the Charter, human rights legislation, and the CRPD. It was also intended to reflect the social model of disability, which acknowledges that "it is the barriers created by society that prevent people with disabilities from enjoying their human rights on an equal basis with others."43

Accordingly, the ACA states that a barrier "hinders the full and equal participation in society" of persons with a variety of impairments. 44 Barriers can include "anything" physical, architectural, technological or attitudinal, anything that is based on information or communications or anything that is the result of a policy or a practice."45 This definition is also inclusive and reflects the diverse experiences of persons with disabilities.

The ACA provides an opportunity to examine the regulation making process through a substantive equality lens, similar to the way courts or tribunals may examine the resulting regulations once they are enacted. Courts can evaluate government programs, policies, laws, and regulations based on substantive equality considerations that could have been addressed during their development. In *Moore*, the Supreme Court of Canada confirmed that wide-reaching government programs, such as health care or education, are services in the context of human rights law. 46 As well, in First Nations Child and Family Caring Society of Canada v Canada (Minister of Indian Affairs and Northern Development), the Canadian Human Rights Tribunal held that funding constitutes a service as well.<sup>47</sup> Considering these two cases, the Ontario Divisional Court recently stated that:

Moore and Caring Society make clear that governments have a proactive human rights duty to prevent discrimination which includes ensuring their funding policies, programs and formulas are designed from the outset based on a substantive equality analysis and are regularly monitored and updated.<sup>48</sup>

<sup>&</sup>lt;sup>43</sup> Bill C-81, "An Act to ensure a barrier-free Canada", 2nd reading, House of Commons Debates, 42-1, No 321 (21 November 2018) at 1525 (Hon Carla Qualtrough)

<sup>&</sup>lt;sup>44</sup> ACA, above, s 2. This section also specifically states that this definition applies to "persons with an impairment, including a physical, mental, intellectual, cognitive, learning, communication or sensory impairment or a functional limitation."

<sup>45</sup> Ibid

<sup>&</sup>lt;sup>46</sup> Moore v British Columbia (Education), 2012 SCC 61 at paras 28-30 [Moore]

<sup>&</sup>lt;sup>47</sup> The Canadian Human Rights Tribunal states that, "there is no indication in the *CHRA* or otherwise that Parliament intended to exclude funding from scrutiny under the Act, subject of course to the funding being determined to be a service. In line with Kelso, where the Government of Canada is involved in the provision of a service, including where the service involves the allocation of funding, that service and the way resources are allocated pursuant to that service must respect human rights principles": First Nations Child and Family Caring Society of Canada v Canada (Minister of Indian Affairs and Northern Development), 2016 CHRT 2 at para 44, see also paras 40-43, 45

<sup>&</sup>lt;sup>48</sup> Ontario v Association of Ontario Midwives, 2020 ONSC 2839 at para 189 (Div Ct)

The Divisional Court made this observation regarding Ontario's discriminatory compensation of midwives. However, it is reasonable to extend the court's general statement of the law to apply to regulation-making processes as well.

Minister Qualtrough stated that the *ACA* "will help develop a system in which the Government of Canada and the industry are required to anticipate barriers before they can limit access to persons with disabilities."<sup>49</sup> This proactive approach should also apply to the development of regulations, where regulators anticipate and remove barriers that prevent persons with disabilities from participating.

In summary, ARCH brings a substantive equality perspective to its work on this project. This approach is consistent with the *ACA* and the objectives of this project. Regulators must take into account the perspectives of persons with disabilities, consistent with the *Charter* and Canadian human rights and equality law. They must proactively promote inclusion of persons with disabilities in accordance with the *ACA* and the *CRPD*.

### The ACA's Principles, Substantive Equality, and the CRPD

When developing accessibility regulations, regulators must be guided by the purpose of the *ACA* and its principles. These principles are set out in section 6 of the *ACA*. They reflect the understanding of substantive equality described above, including the concepts of equality; participation in society; taking into account the social model of disability, intersecting forms of marginalization and discrimination; and proactive involvement of people with disabilities in the development and design of laws, policies and programs.

These principles must be considered by regulated entities when creating accessibility plans. They should also serve as guidance for regulators when developing the content of new accessibility regulations and when determining how to conduct regulatory development in the most accessible, inclusive manner.

The *CRPD* is of particular relevance when interpreting and applying the *ACA* principles. Article 9(1) of the *CRPD* provides that State Parties:

shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications

<sup>&</sup>lt;sup>49</sup> Bill C-81, "An Act to ensure a barrier-free Canada", 3rd reading, *House of Commons Debates*, 42-1, No 355 (19 September 2018) at 1530 (Hon Carla Qualtrough)

technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.<sup>50</sup>

Article 9(2)(a) of the *CRPD* explains that State Parties should "[d]evelop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public."<sup>51</sup> These articles of the *CRPD* are explicitly recognized in the preamble to the *ACA*, showing that Parliament intended the *ACA* to implement these *CRPD* obligations. To give effect to this intention, the *ACA* must be interpreted consistently with the *CRPD*.<sup>52</sup> Moreover, Canadian law has long held that Canada's international law obligations are an important and relevant source when interpreting domestic law, and that where possible, domestic law should be interpreted in a manner that is consistent with Canada's international obligations.<sup>53</sup>

When seeking to understand and apply the section 6 principles, regulators should also consider commentary of the UN Committee on the Rights of Persons with Disabilities, known as General Comments.<sup>54</sup> General Comments are relevant to understand the meaning and normative content of *CRPD* articles, and how they apply in the domestic context.<sup>55</sup>

<sup>&</sup>lt;sup>50</sup> CRPD, above art 9(1)

<sup>&</sup>lt;sup>51</sup> *Ibid*, art 9(2)(a)

<sup>&</sup>lt;sup>52</sup> Ruth Sullivan, *Sullivan on the Construction of Statutes*, 6th ed (Markham: Lexis-Nexis, 2014) at 585-596. Sullivan cites *National Corn Growers*, along with other cases, and explains that legislation implementing an international convention should be interpreted consistent with the convention where possible, even if there is no ambiguity.

stated that: [i]n interpreting legislation which has been enacted with a view towards implementing international obligations, as is the case here, it is reasonable for a tribunal to examine the domestic law in the context of the relevant agreement to clarify any uncertainty. Indeed where the text of the domestic law lends itself to it, one should also strive to expound an interpretation which is consonant with the relevant international obligations": *National Corn Growers Assn v Canada (Import Tribunal)*, [1990] 2 SCR 1324 at 1371 [*National Corn Growers*]. Justice Gonthier also explains in the following paragraph that the implementing statute is not required to be ambiguous on its face for this principle to apply. See also: *Re: Sound v Motion Picture Theatre Associations of Canada*, 2012 SCC 38 at para 51. The presumption of conformity was recently confirmed by the Supreme Court of Canada in a decision relating to the interpretation of the *Charter* based on international instruments. While the Court emphasized the importance of Canadian law in interpreting the Charter, it acknowledged that treaties that Canada has ratified, such as the *CRPD* may also play a role: *Quebec (Attorney General) v 9147-0732 Québec inc*, 2020 SCC 32 at paras 31-32, 34

<sup>&</sup>lt;sup>54</sup> United Nations Committee on the Rights of Persons with Disabilities, "General Comments", online: https://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx

<sup>&</sup>lt;sup>55</sup> The United Nations Committee on the Rights of Persons with Disabilities has authored General Comments interpreting article 5 (equality and non-discrimination), article 6 (women and girls with disabilities), article 9 (accessibility), article 12 (equal recognition before the law), article 19 (right to independent living), article 24 (right to inclusive education), and articles 4.3 and 33.3 (participation of persons with disabilities in the implementation and monitoring of the Convention).

## Part IV: Barriers and Solutions in Regulation Development Processes Identified in the Research

Section 6(f) of the *ACA* requires that "persons with disabilities must be involved in the development and design of laws, policies, programs, services and structures". <sup>56</sup> This part of our report discusses what it means to "involve" persons with disabilities in regulation making processes, with reference to section 6(f) and other section 6 principles, including dignity; diverse participation and recognition of intersectional identities; and accountability, which is necessary to achieve the section 6(g) principle of "the highest level of accessibility for persons with disabilities". The analysis that follows synthesizes the findings of our legal research, the qualitative research conducted by McGill, and work with our disability community project partners.

### Conceptualizing Regulation Development from the Perspective of Persons with Disabilities

To understand how to make regulation development more accessible and inclusive, first, it is important to briefly review regulation making from the perspective of a participant with a disability. The Cabinet Directive on Regulation sets out the process for regulation development that is followed by the Government of Canada and the Canadian Transportation Agency. It outlines two opportunities for persons with disabilities to take part during regulation development: pre-consultations and public comment.<sup>57</sup> Regulators also refer to these opportunities for stakeholders to give feedback on regulations using more general terms, such as consultations or engagement processes.

In the early stages of regulation-making, a person with a disability might find out about pre-consultations through a government website, by reading a press release, or through social media. At this stage, the regulator is likely seeking information about the goals of its regulation and the general approaches it will use to achieve them.<sup>58</sup> This preconsultation may involve in-person meetings, teleconferences, or writing a submission.

<sup>&</sup>lt;sup>56</sup> *ACA*, above, s 6(f)

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<sup>&</sup>lt;sup>57</sup> Cabinet Directive on Regulation, Treasury Board Secretariat, in force as of September 1, 2018 (consulted on July 11, 2019), online: <a href="https://www.canada.ca/en/treasury-board-secretariat/services/federal-regulatory-management/guidelines-tools/cabinet-directive-regulation.html">https://www.canada.ca/en/treasury-board-secretariat/services/federal-regulatory-management/guidelines-tools/cabinet-directive-regulation.html</a>.

<sup>58</sup> *Ibid* 

After the pre-consultations are complete, the person with a disability may not receive any updates about the regulation for a while. They might be told that the government or regulator is analyzing and drafting the regulation,<sup>59</sup> but any details are confidential.

Months later, they may find the draft regulation pre-published in Part I of the Canada Gazette, the official newspaper of the Government of Canada. This draft regulation is published with a Regulatory Impact Analysis Statement (RIAS), which describes the government or regulator's analysis of that draft regulation.<sup>60</sup>

The person with a disability might learn that, at this public comment stage, the regulator is seeking further feedback before the regulation is finalized.<sup>61</sup> The person with a disability might provide this input, likely in writing.

After more time passes and more confidential government decisions are made, they may find the final regulation and the final RIAS published in Part II of the Canada Gazette.<sup>62</sup>

A person with a disability may also participate in regulation-making at the Canadian Transportation Agency through the Accessibility Advisory Committee. <sup>63</sup> The Agency's Accessibility Advisory Committee is made up of persons with disabilities, industry, and two government agencies, the Canadian Air Transport Security Authority and the Canada Border Services Agency. The Agency consults directly with its Accessibility Advisory Committee about new regulations. For example, it may hold in-depth discussions in meetings of the committee to get their input on the regulation.

A person participating in the development of a regulation by the Canadian Radio-television and Telecommunications Commission may have a slightly different experience. The CRTC does not follow the Cabinet Directive on Regulation, although its process has the same two opportunities to participate: one at the policymaking stage and another once the draft regulation has been published. At each stage, the person with a disability could provide a written submission and comment on submissions by others. <sup>64</sup> Very rarely, that person may have the opportunity to participate in an oral hearing. <sup>65</sup>

60 Ibid

<sup>&</sup>lt;sup>59</sup> Ibid

<sup>61</sup> Ibid

<sup>62</sup> Ibid

<sup>&</sup>lt;sup>63</sup> Canadian Transportation Agency, "Accessibility Advisory Committee", online: <a href="https://otc-cta.gc.ca/eng/accessibility-advisory-committee">https://otc-cta.gc.ca/eng/accessibility-advisory-committee</a>

<sup>&</sup>lt;sup>64</sup> Canadian Radio-television and Telecommunications Commission Rules of Practice and Procedure, SOR/2010-277. Also go to Canadian Radio-television and Telecommunications Commission, Broadcasting and Telecom Information Bulletin CRTC2010-959, "Guidelines on the CRTC Rules of Practice and Procedure", online: <a href="https://crtc.gc.ca/eng/archive/2010/2010-959.htm#z1">https://crtc.gc.ca/eng/archive/2010/2010-959.htm#z1</a>; Canadian Radio-

Persons with disabilities may encounter barriers at each of these stages of regulation development. This may mean that they cannot participate at all, or their participation is limited in ways that affect the input that they can provide. Academic literature demonstrates that involvement of persons with disabilities in government policy development has the potential to have a real and perceived effect on government action. However, sometimes that does not happen in practice. For example, in the context of reforms to income support for persons with disabilities in Alberta, Claudia Malacrida and Stefanie Duguay observed that:

although the government claimed to seek the input of people with disabilities, they precluded citizen participation by late inclusion, exclusionary and intimidating environments, inaccessible language and format and input that was limited by the format of the review.<sup>67</sup>

### Section 6(f): Involvement of Persons with Disabilities in the Development and Design of Laws

Section 6(f) of the *ACA* states that the, "...Act is to be carried out in recognition of, and in accordance with, the following principles [...] persons with disabilities must be involved in the development and design of laws, policies, programs, services and structures. What does "involving" persons with disabilities in regulation making processes require? Our research shows that involvement means continuous, transparent, and meaningful participation, with appropriate resources and supports. Moreover, it requires active participation with the opportunity for discussion and dialogue.

#### A Continuous Process

The UN Committee on the Rights of Persons with Disabilities describes participation of persons with disabilities in law-making processes as an ongoing, continuous process, rather than a one-time event.<sup>68</sup> This means that regulators must provide multiple

television and Telecommunications Commission, "Your Roadmap to CRTC Processes in ASL", online: <a href="https://crtc.gc.ca/eng/info\_sht/transcript.htm">https://crtc.gc.ca/eng/info\_sht/transcript.htm</a>

<sup>66</sup> Elaine Jurkowski, Borko Jovanovic & Louis Rowitz, "Leadership/Citizen Participation" (2002) 14:4 Journal of Health & Social Policy 49 at 58-59

<sup>65</sup> Ibid

<sup>&</sup>lt;sup>67</sup> Claudia Malacrida & Stefanie Duguay, "'The AISH review is a big joke': contradictions of policy participation and consultation in a neo-liberal context" (2009) 24:1 Disability & Society 19 at 30 <sup>68</sup> General Comment No 7, above at para 28. Similarly, the Law Commission recommends that governments take steps "to ensure that all stages of public consultation are accessible to persons with disabilities: Law Commission of Ontario, above 12

opportunities for persons with disabilities to participate in regulation development, throughout the process.

An ongoing, continuous process would address some of the barriers identified by the qualitative research. The qualitative research found that some participants felt that engagement meetings for regulatory consultations were too long, others found that there was not enough time to engage in dialogue, and consultations were often held too close together. Engagement processes that were "too technical, complex, long or intensive" or clustered together also contributed to consultation fatigue.<sup>69</sup> In the words of the research participants:

"A lot of the consultations if they're day-long meetings, they are very difficult. We are able to do them but it takes us a week to work up to getting there. So we know we're going to this meeting, so we need to rest more, we need to prepare for it. And then you can't book all kinds of other meetings the week following because you're so exhausted and people don't realize that."

"One day of consultations is too short ... at least be two days to be able to really get through and have those meaningful discussions."

"I struggle to find words, and sometimes it takes me longer to get my thoughts together, and they've already moved to another topic by the time I get my thought together. I stop the meeting and say, 'Sorry I was trying to get it out, so we need to go back.' If people were aware, a lot of people would do that."<sup>70</sup>

A continuous and coordinated process would facilitate participation in response to these concerns. It would ensure that meetings and requests for written submissions are not clustered together, but instead coordinated among the regulators so as not to exacerbate consultation fatigue. It also would allow for more opportunities for shorter meetings that accommodate the needs of participants with disabilities and also provide, over time, the opportunity to discuss important issues in depth.

### A Transparent Process

Continuous involvement is complemented by open and responsive communication whenever possible during the regulatory development process, a requirement that is highlighted by the UN Committee on the Rights of Persons with Disabilities.<sup>71</sup> For example, clear, plain language communication of the steps of the regulator's process and its timelines will allow participants with disabilities to better understand their role

<sup>70</sup> Movahed *et al*, above at 19-20

<sup>69</sup> Movahed et al, above at 25

<sup>&</sup>lt;sup>71</sup> *Ibid* at paras 23, 33; Löve *et al*, above at 9-10

and give helpful feedback.<sup>72</sup> Conversely, lack of transparency regarding the regulation development process creates barriers for persons with disabilities and undermines trust.

The McGill qualitative research found that participants expressed frustration with the lack of transparent information regarding the objective of engagement processes and the feedback that was sought by regulators:

"We try to understand what exactly the objective was, the feedback that was requested from us. I got the sense that ... the government didn't know what they wanted either, so they weren't able to provide us with any directions." <sup>73</sup>

In particular, broad questions asked by government and lack of clear guidance about the consultation's scope led to discussion of irrelevant information.<sup>74</sup> This information may be extremely important in terms of understanding the perspectives and living experiences of people with disabilities generally, but if it is outside the scope of what the particular regulation can address, it is not relevant for the purposes of the regulatory development process. Clearer questions and information about the goals and the scope of the engagement would have led to less confusion regarding the input that was requested by regulators.<sup>75</sup>

The McGill researchers also observed that, "[t]here was an overall lack of clarity about the potential impact of [the participants'] contributions in regulations and policy development, compromising trust in the process." This demonstrates that transparency is directly connected to the degree of confidence that participants have about whether their feedback will be taken seriously.

These results are consistent with the independent reviews of provincial standards development processes in Ontario and Manitoba. In both provinces, the reviewers stated that an overly broad and open-ended description of the process and the relevant tasks undermined efficiency and effectiveness.

In Ontario, the terms of reference and the timelines for the standards development committees were vague.<sup>77</sup> As a result, in his independent review of the *AODA*, Charles Beer recommended a clearer structure and accountability framework outlining the scope

<sup>72</sup> General Comment No 7, above at para 94e and u

<sup>73</sup> Movahed et al, above at 20

<sup>74</sup> Movahed et al, above at 21

<sup>&</sup>lt;sup>75</sup> *Ibid* at 20, 22

<sup>&</sup>lt;sup>76</sup> *Ibid* at 11

<sup>&</sup>lt;sup>77</sup> Charles Beer, "Charting a Path Forward: Report of the Independent Review of the Accessibility for Ontarians with Disabilities Act: a report by Charles Beer on his findings and recommendations for improving the effectiveness of Ontario's accessibility laws" (2009), online:

https://www.ontario.ca/page/charting-path-forward-report-independent-review-accessibility-ontarians-disabilities-act (not paginated)

of the committees' tasks.<sup>78</sup> He also recommended "[m]ore transparent timelines for the development of the standards and ongoing assessment of the feasibility of timelines."<sup>79</sup>

In Manitoba, there was also a lack of clarity about the nature of the standards development process and its timelines. In her independent review of *The Accessibility for Manitobans Act*, Theresa Pruden stated that the process "is cumbersome and protracted, and has not been well understood even by some members of standard development committees." She was also concerned about the length of the standards development process in Manitoba and recommended clarity regarding timelines and more attention to efficiency. 81

In summary, transparent information about the goals and scope of the engagement process, the feedback sought from participants, and the timelines would facilitate participation in regulation development. Meanwhile, lack of clarity on these topics is a significant barrier for persons with disabilities and undermines their trust in the process.

### Early Involvement and Potential for Real Impact

Regulators must consider involving persons with disabilities early in the regulatory development process,<sup>82</sup> when they have a greater opportunity to influence decisions about regulatory concepts and language. The literature shows that when a conclusion has essentially already been reached by regulators, persons with disabilities feel that their opinions and participation are not valued, and that their participation is not meaningful.<sup>83</sup>

Consistent with this literature, some of the McGill study participants felt that their contributions were not viewed as important. Rather than developing policy with accessibility in mind from the outset, they expressed that governments treated it as a secondary concern. One participant said:

"The fact that they had us in the room is good. I think it is important that we were there and that we were seen. But disability is a lot bigger than just having one or two organizations in a room. So I think that there's still a lot more work to be done, disability affects everybody, so having accessibility built into already like

79 Ibid

<sup>78</sup> Ibid

<sup>&</sup>lt;sup>80</sup> Theresa Pruden, "Independent Report on the Effectiveness of the Implementation of The Accessibility for Manitobans Act" (December 2018) at 15, online: <a href="http://www.accessibilitymb.ca/pdf/ama-review.pdf">http://www.accessibilitymb.ca/pdf/ama-review.pdf</a>
<sup>81</sup> Pruden, above at 16, 18-19

<sup>82</sup> General Comment No 7, above at para 43

<sup>&</sup>lt;sup>83</sup> William Sherlaw & Hervé Hudebine, "The United Nations Convention on the rights of persons with disabilities: Opportunities and tensions within social inclusion and participation of person with disabilities" (2015), 9:1 European Journal of Disability Research 9 at 16; Löve *et al*, above at 9; Löve, Traustadóttir & Rice, above at 3, 6. See also Law Commission of Ontario, above at 11-12

at the forefront of how you know they're going to be creating policy and coming up with ideas. It's usually an afterthought, it's like, Oh wait yeah we have these ideas, oh wait are they accessible?"84

Persons with disabilities often feel that the feedback they provide during regulation making is not valued by regulators. Participants in the McGill research expressed that, "the government was not receptive to anything new that the participants had to say".85 Similarly, in a study conducted in Iceland, a participant stated that: "sometimes it feels to me as if it's pro forma. They have to include us. And then it's like decisions have already been made at some kind of pre-meeting."86 This is a common barrier in the academic literature, that is also consistent with the observations of our project partners.

To address this problem, regulators should follow the recommendation of the UN Committee on the Rights of Persons with Disabilities to approach the process with an open mind, such that persons with disabilities are not "heard as a mere formality".87 Based on our research, one way that regulators may be able to accomplish this is by involving persons with disabilities early, when their input has a greater potential to influence the content of the regulation. Lepofsky and Graham recommend early involvement of persons with disabilities, since the potential for problem-solving is greater.88 In contrast, later on, "there may be resistance to making changes to a bill or policy, though needed to make it barrier-free, because so many players within government are already invested in the product already drafted."89

In summary, involvement of persons with disabilities requires gathering feedback early, when there is more potential for feedback to have a real impact, in addition to other stages of the regulation making process. It also requires regulators to proactively consider disability related issues during the regulation development process, rather than turning their mind to these issues after a regulation has been drafted or regulatory goals have been determined.

#### Facilitated Discussion with Meaningful Dialogue

Article 4(3) of the *CRPD* elaborates that, in the development of legislation and policies that affect persons with disabilities, State Parties "shall closely consult with and actively involve" them. 90 To interpret this article consistent with its plain meaning, "active

<sup>84</sup> Movahed et al. above at 21

<sup>85</sup> *Ibid* at 22

<sup>86</sup> Löve et al, above at 9

<sup>87</sup> General Comment No 7, above at para 48

<sup>88</sup> David Lepofsky & Randal Graham, "Universal Design in Legislation: Eliminating Barriers for People with Disabilities" (2009), 30:2 Statute Law Review 129 at 154 89 Ibid

<sup>&</sup>lt;sup>90</sup> *CRPD*, above, art 4(3)

involvement" must mean more than close consultation. It also must mean more than the one-way, often written processes, that are frequently employed in federal regulatory development. Instead, it requires a two-way discussion or dialogue that empowers persons with disabilities and enables policymakers to better understand their contributions.

The McGill research study demonstrates the importance of this active, "two-way" involvement. Participants expressed frustration that regulatory development meetings were framed and facilitated in a way that did not allow for two-way dialogue.<sup>91</sup> The study recommended small group settings focused on a specific topic.<sup>92</sup> It also suggested that facilitators should be "a positive force" in consultation meetings.<sup>93</sup> They could do this by asking participants to give their names before speaking, clearly outlining topics and questions, and ensuring that all participants have the opportunity to contribute.<sup>94</sup>

Our project partners also expressed that a facilitated discussion may be helpful in promoting more active participation. They recommended that facilitators should be persons with disabilities or have significant experience working with communities of people with disabilities. This would enable facilitators to break down barriers, and encourage meaningful dialogue and exchange between regulators and people with disabilities.

An "active", two-way process that promotes dialogue through discussion, focus groups or working meetings is likely to yield more meaningful participation than passive written feedback processes. <sup>95</sup> Two-way discussions allow difficult issues to be discussed

95 The Voices of Individuals: Collectively Exploring Self-determination (VOICES) Project, based at the Centre for Disability Law and Policy, led by Professor Eilionóir Flynn, exemplifies active involvement. The project focused on the right to legal capacity, outlined in article 12 of the CRPD: Clíona de Bhailís. "Theoretical Framework for the VOICES Project", eds Eilionóir Flynn et al, Global Perspectives on Legal Capacity Reform: Our Voices, Our Stories (Routledge: Abingdon, 2019) 1 at 1-8. It paired storytellers possessing living experience with respondents with diverse personal experience. Storytellers wrote narratives and respondents wrote responses about specific topics relevant to the project's theoretical framework. The project produced an edited collection of these narratives and responses: Eilionóir Flynn, "Project methodology and background", eds Eilionóir Flynn et al, Global Perspectives on Legal Capacity Reform: Our Voices, Our Stories (Routledge: Abingdon, 2019) 9 at 9-15. The experience of respondents included living experience, as well as professional backgrounds in varying disciplines. However, it was also committed to ensuring that these stories had the potential to effect change. In this regard, the VOICES Project then matched participants with policymakers positioned in leadership roles with the authority and influence to make actual change. Before the participants met the policymakers, the researchers discussed ground rules as well as the backgrounds of the policymakers. The storytellers and respondents worked together to anticipate potential obstacles to change that a policymaker could raise, and how they could respond. They also identified the information that was most important for the policymakers to understand. The policymakers then met with the participants. After these meetings, the researchers held a session for feedback and reflection, asking each policymaker to commit to making one

<sup>&</sup>lt;sup>91</sup> Movahed et al, above 20, 22

<sup>92</sup> Ibid at 30.

<sup>93</sup> *Ibid* at 27

<sup>94</sup> Ibid

productively, in a way that encourages problem-solving. In his discussion of the Ontario standards development process, David Lepofsky stated that, "[o]n more important and contentious issues, there is no substitute for frank face-to-face exchanges." <sup>96</sup>

In addition, our project partners and participants in the McGill research study raised ideas of co-creation and collaboration in the context of regulation making.<sup>97</sup> These ideas are important to consider, since they reflect a role for persons with disabilities that encourages mutual exchange of information in a way that meaningfully informs the development of the regulation. While the ability of regulators to implement co-creation or collaboration within current regulatory development frameworks may be limited, these ideas are discussed in our recommendations in the context of future reforms.

### Resources and Supports Relevant to the Proposed Regulation

To participate effectively in regulatory development, persons with disabilities may also require technical resources and supports regarding the proposed regulation. These technical supports and resources must be responsive to the diverse needs of persons with disabilities. For example, according to the UN Committee on the Rights of Persons with Disabilities, existing or historical barriers to inclusive education may mean that persons with disabilities do not enter a regulatory consultation on an equal basis as others. Participation cannot be meaningful where stakeholders have no real opportunity to affect the outcome because they do not have access to relevant knowledge and skill-development opportunities. Addressing barriers to inclusive education are one example of the varied and complex spectrum of supports, technical resources, and accommodations that persons with disabilities may require to participate in regulation development.

For example, Charles Beer's report revealed that a lack of support and resources for the Ontario standards development committees undermined their ability to function properly. In particular, this affected individuals with disabilities who did not have the same access to resources and technical and legal advice that industry representatives

small change to implement article 12: The positions, professions and backgrounds of the policy-makers were diverse, ranging from transportation to banking to education to guardianship: VOICES Project, online: <a href="https://ercvoices.com/resources/toolkit/outputs-and-impact-2/">https://ercvoices.com/resources/toolkit/outputs-and-impact-2/</a>. The VOICES Project shows how personal stories, living experience, and expertise of persons with disabilities can play a powerful role in law and policymaking. It also shows how persons with disabilities may be meaningfully included to impart their personal perspectives, knowledge, and expertise. It demonstrates the power of building community capacity, and its great potential, over time, to lead to helpful input by persons with disabilities.

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<sup>&</sup>lt;sup>96</sup> David Lepofsky, "What Should Canada's Proposed Accessibility Law Include? A Discussion Paper" (2018) 38:1 NJCL 169 at 186

<sup>&</sup>lt;sup>97</sup> Movahed et al, above at 28

<sup>98</sup> General Comment No 7, above at paras 58-60

<sup>99</sup> Löve, Traustadóttir & Rice, above at 6; see also Löve et al, above at 11

<sup>&</sup>lt;sup>100</sup> Beer, above

did. In response to these concerns, Beer recommended "engagement of appropriate technical and sectoral expertise", "credible background documents [...] about evidence-based and best practices", and "establishment of a formal orientation and training program for committee members."<sup>101</sup>

Our project showed a particular need for two types of resources and supports to facilitate meaningful participation of people with disabilities in the development of regulations: accessible background information and skills development opportunities to build greater capacity within disability communities.

### Accessible Background Information for Regulatory Consultations

The McGill research highlighted a variety of barriers associated with the background information for regulation development processes. First, the participants found the amount of information given by regulators to be overwhelming. One participant stated that:

"The government released the draft legislation which maybe it was 100 pages or more, highly technical and difficult to get through if you have a university education. They also provided a plain language version which was absolutely inappropriate and unacceptable." 103

Second, participants found there was not enough time to review the background information and to consult with other members of disability communities to gather their feedback:

"It wasn't well in advance ... maybe it was two or three days before the meeting. ... I wish I had more time to consult with our community and so that it would be better in terms of the information I could bring to the table." 104

Third, the use of technical terms and acronyms made the background information difficult to understand. These findings are also consistent with academic literature

<sup>&</sup>lt;sup>101</sup> Beer, above. After changes were made, David Onley reported mixed feedback. Some participants found the orientation and technical expertise useful, while some disability representatives state that they may have benefited from more supports: David Onley, "2019 Legislative Review of the Accessibility for Ontarians with Disabilities Act, 2005" (2019) at 29, online: <a href="https://www.ontario.ca/page/2019-legislative-review-accessibility-ontarians-disabilities-act-2005">https://www.ontario.ca/page/2019-legislative-review-accessibility-ontarians-disabilities-act-2005</a>

<sup>&</sup>lt;sup>102</sup> Movahed *et al*, above at 23

<sup>&</sup>lt;sup>103</sup> *Ibid* at 11

<sup>104</sup> *Ibid* at 24, also go to 11

<sup>&</sup>lt;sup>105</sup> *Ibid* at 23

that identifies jargon and technical language as barriers for persons with disabilities in policymaking processes.<sup>106</sup> In the words of the McGill study participants:

"Things that are just really complex concepts and there are ways to bring it down to more common language. I know I can't get excited about stuff if I have to Google different words out of the questions that are supposed to be important to me and I don't know what they mean."

"It was very technical; it would have been better in plain language. They used a lot of acronyms. If you want to get input from people, they are barriers even if people know what they are." 107

Third, background information was not always provided in accessible formats. For example, in some regulatory development processes, there was no sign language version, making the information inaccessible for Deaf persons. Electronic documents could not be accessed with a screen reader, pictures were not accompanied by text descriptions and websites and online forms were not accessible to persons who are blind or have low vision.<sup>108</sup>

Inaccessible background information makes it particularly difficult for persons with disabilities who are not affiliated with organizations to participate. Without the institutional knowledge and resources that a large organization may have, the barriers to participation are often all the more significant.

Participants in the McGill study expressed that large organizations "know the timeline, we know what the government people are up to, we are following this day to day", 109 while smaller organizations or individuals may not have this experience, knowledge and resources. This made it more difficult for them to understand how the process works, identify problems that were relevant to the regulation, and propose solutions to those problems:

"They didn't make the process clear, which was fine for us because we do a lot of work in this area, but again other organizations or individuals themselves or persons with lived experience wouldn't know that cycle of legislation and therefore could be very confused."<sup>110</sup>

The McGill researchers concluded that accessible background information should be made available several weeks in advance of a regulatory consultation, must be

109 Ibid at 14

<sup>&</sup>lt;sup>106</sup> Robert F Drake, "Disabled people, voluntary organisations and participation in policy making" (2002) 30:3 Policy & Politics 373 at 380; Malacrida & Duguay, above at 27

<sup>&</sup>lt;sup>107</sup> Movahed et al, above at 23

<sup>&</sup>lt;sup>108</sup> *Ibid* 

<sup>&</sup>lt;sup>110</sup> *Ibid* at 11

available in multiple, accessible formats, and must provide information such as the agenda for a meeting, the goals of the regulation, a draft regulation if it exists, background notes, and expectations of participants.<sup>111</sup> It is important that the main points be conveyed clearly and concisely in clear, non-technical language.<sup>112</sup> The researchers emphasized the importance of recognizing intersectional perspectives in the design of background materials.<sup>113</sup>

Our project partners also highlighted the importance of accessible background resources provided at least two weeks in advance, that would enable them to understand the regulatory development process and technical information relevant to the regulation.

### Skills Training and General Resources to Support Capacity Building

Our legal research and the results of the McGill study demonstrated a need for training, information, tools and other resources to support capacity building for disability organizations and persons with disabilities. Skills training could address regulation development or technical matters relevant to the subject matter of particular accessibility regulations. <sup>114</sup> It could also focus on communication and negotiation skills relevant to providing feedback in person or in writing. <sup>115</sup> Building the skills and knowledge that facilitate meaningful participation in regulation development would empower communities of persons with disabilities as they question assumptions and develop their expertise. <sup>116</sup>

In the McGill study, participants identified that it may be important for some persons with disabilities, especially those who are not affiliated with organizations, to have training in public speaking before attending a meeting:

"It depends on how they are comfortable of their own disability and if they haven't come forward and express their needs and haven't done any of that and they don't belong to a group of people, then it's gonna be really difficult."117

In contrast, with appropriate resources and supports, persons with disabilities will be able to participate more confidently and effectively:

112 Ibid

113 *Ibid* at 31

<sup>111</sup> Ibid at 27

<sup>&</sup>lt;sup>114</sup> General Comment No 7, above at para 58; Movahed et al, above at 12

<sup>&</sup>lt;sup>115</sup> General Comment No 7, above para 58-60; Löve et al, above at 10-11

<sup>&</sup>lt;sup>116</sup> Rita Samson, "Securing the Full Participation of Persons with Disabilities and their Representative Organizations in Disability Rights Monitoring" in Marcia Rioux, Paula Pinto & Gillian Parech, eds, *Rights Monitoring and Social Change: Building Power out of Evidence* (Toronto: Canadian Scholars Press, 2015) 238 at 246; General Comment No 7, above at para 58

<sup>&</sup>lt;sup>117</sup> General Comment No 7, above at 12

"Providing more information would probably help people engage better. This is particularly very helpful for organizations or individuals who don't know the legal technicalities and how laws work."

"Then participants feel equipped and empowered to participate ... feel comfortable to speak out and really bring in their voices." 118

Our research relating to accessible background information and skills development resources has informed the development of the educational materials for this project. We are also hopeful that our research will inform the development of additional resources to build community capacity through other projects. We discuss some of these initiatives in Part V of this Final Report.

### Section 6(a): Dignity in Regulation Development Processes

Section 6(a) states that the *ACA* must be carried out in accordance with the principle that "all persons must be treated with dignity regardless of their disabilities." <sup>119</sup> As described above, the Supreme Court of Canada has recognized that human dignity is an "essential value" underlying the equality guarantee of the *Charter*. <sup>120</sup> In this regard, persons with disabilities are denied dignity when they are subjected to stereotypes or barriers to full participation in society. <sup>121</sup> While certain barriers may be created unintentionally, they nonetheless portray "a devalued image of [persons with disabilities] by failing to recognize them as human beings". <sup>122</sup> Canadian law has consistently found that intention is not relevant to an analysis of discrimination, and the focus on the inquiry should be on the impact of a law, policy, or practice. <sup>123</sup>

How can the dignity principle be applied when involving persons with disabilities in regulation making processes? According to our research, four elements of the regulatory development process that are particularly relevant to dignity are: universal design and accommodations in regulatory engagement processes; recognition of the expertise of persons with disabilities; connecting living experience with regulations being developed; and compensation for expertise.

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<sup>118</sup> Ibid at 27

<sup>&</sup>lt;sup>119</sup> *ACA*, above, s 6(a)

<sup>&</sup>lt;sup>120</sup> Kapp, above at para 21

<sup>121</sup> Quebec (Attorney General) v A, 2013 SCC 5 at para 199

<sup>122</sup> Ibid

<sup>&</sup>lt;sup>123</sup> For example, *Andrews v Law Society of British Columbia*, [1989] 1 SCR 143 at 174, quoted more recently in *Kapp*, above at para 18

#### Universal Design and Individual Accommodations in Regulation Development

Universal design refers to designing a system or process to be accessible to everyone, from the outset.<sup>124</sup> The McGill research study showed that opportunities to universally design consultations and engagement were sometimes missed and individual accommodations were not always available in regulation development processes.<sup>125</sup> These problems undermine respect for the dignity of persons with disabilities and impose unnecessary barriers to their participation.

The McGill researchers reviewed feedback from participants with a variety of disabilities to identify their particular concerns. For example, Deaf persons did not always receive American Sign Language or langue des signes Québécoise interpretation, the interpretation was not always high quality, and the room for in-person meetings could get too noisy. 126 Participants with communication disabilities also raised concerns about the noise level of the room, as well as the failure to provide plain language information. 127 Participants with vision disabilities explained that written materials were not always accessible for screen reader software or not available in Braille. They found that sometimes it was difficult to find the room for an in-person meeting because of inaccessible signage and wayfinding, and they did not always have access to technology, such as wireless internet, a computer, or screen reader software. 128 Participants who identified as deaf-blind expressed that teleconferences were difficult and they did not always have deaf-blind intervenors at meetings. 129 Persons labelled with intellectual disabilities explained that materials were often overwhelming and not in plain language, and they experienced ableist attitudes that they were less capable of participating than others. 130

The participants also explained how individual accommodations should be arranged. These considerations included giving interpreters background information about the consultation, always having accessible formats available, and moderating noise levels:

<sup>124</sup> The Centre for Excellence in Universal Design describes universal design as "...the design and composition of an environment so that it can be accessed, understood and used to the greatest extent possible by all people regardless of their age, size, ability or disability. An environment (or any building, product, or service in that environment) should be designed to meet the needs of all people who wish to use it. This is not a special requirement, for the benefit of only a minority of the population. It is a fundamental condition of good design. If an environment is accessible, usable, convenient and a pleasure to use, everyone benefits...." Online: <a href="http://universaldesign.ie/What-is-Universal-Design/">http://universaldesign.ie/What-is-Universal-Design/</a>. Principles of universal design have been applied to the built environment, services, education, legislative drafting and other areas of life.

<sup>125</sup> Movahed et al, above at 29

<sup>&</sup>lt;sup>126</sup> *Ibid* at 15

<sup>&</sup>lt;sup>127</sup> *Ibid* at 17

<sup>&</sup>lt;sup>128</sup> *Ibid* at 15-16

<sup>&</sup>lt;sup>129</sup> *Ibid* at 16

<sup>130</sup> Ibid at 17

"Interpreters should have foundational background or understanding of political structure and political life, federal and provincial governmental structures; otherwise, they interpret incorrectly. This is a concern, as the message will not be conveyed properly just because of the misinterpretations." <sup>131</sup>

"They did bring some information to the table which they didn't send to me previously electronically; so, you know, I had to have a person next to me basically read it aloud instead of reading to themselves as being presented." 132

"People with Alzheimer and people with autism, they develop sensory problems, so some of us developed something called hyperacusis, so every noise is super loud. Everybody's talking on the side while the main person is talking, well that's so distracting for me." 133

Participants emphasized that it is not just the venue for a meeting that must be accessible, rather regulators must consider how persons with disabilities travel there as well.<sup>134</sup> For example, a participant with a physical disability explained that:

"It is not ideal to have a meeting at supper time for example from 5 pm-7 pm because of the time and arrangement took for Para-transport services, the person has to leave the house at 4 pm and the pick-up is also late, so it took a long time without even having any refreshment at the meeting." 135

Our project partners related their personal stories about accessibility barriers that they experienced when participating in regulation development processes. Similar to the McGill study, their comments reflected that regulators must do better in arranging accommodations and employing universal design. For example, our project partners emphasized the importance of providing trained communication assistants, note-takers, recording and scribing for persons with communication disabilities. They also explained that online forms should not time out quickly and should be compatible with assistive technology like spell checkers or word prediction. They told us that Deaf persons need an accessible way to request assistance and to receive announcements about any changes at the venue. Finally, they explained that sign language interpretation should be provided throughout the entire meeting or hearing, not only the part where a Deaf person is asked to give input.

132 *Ibid* at 16

<sup>&</sup>lt;sup>131</sup> *Ibid* at 15

<sup>&</sup>lt;sup>133</sup> *Ibid* at 17

<sup>134</sup> *Ibid* at 25

<sup>&</sup>lt;sup>135</sup> *Ibid* at 19

That said, our research also shows that some of the efforts that regulators have put in to ensure accessibility are having a positive impact. In describing the venue for a consultation meeting that went well, one McGill study participant said:

"I think they chose an accessible space, though; there was room for a chair, there was an elevator, there were push doors, there was information related, like they had a PowerPoint on the screen, they definitely let people communicate in a way that they felt comfortable to communicate." <sup>136</sup>

The McGill researchers concluded that accommodations to ensure accessibility and engagement processes in multiple formats facilitate the participation of persons with disabilities.<sup>137</sup> In identifying best practices, participants recommended the use of multiple formats for every regulatory consultation, including "face-to-face meetings, teleconferences, town hall meetings, online surveys, use of social media such as Twitter to get people's feedback":<sup>138</sup> Using multiple formats is also a way to offer opportunities for persons with disabilities living in remote and rural locations to participate in regulatory development.

"it's important to have all of those types because each type of event really plays to the strengths of particular groups of people; so, for example, a face-to-face interaction versus one that's on the telephone, face-to-face interaction would accommodate those who can actually get to like face-to-face event which is something on the phone or maybe web based, I mean, that could be across the country, you know, across a particular region if people have transportation barriers."

"I personally favour face-to-face meetings over teleconferences just from an access point of view. I find it difficult. But at the same time, teleconference and town hall, those kinds of things, are a good way to reach people who live outside of major urban centres, and I think that's important too."

The McGill study also demonstrates that regulators should provide more notice for participants to prepare for consultations and for organizations to get feedback from their communities.<sup>139</sup> This recommendation is supported by the academic literature. For example, Malacrida and Duguay compared the full year of notice of the Alberta's government's policy changes that was given to disability agencies to the last-minute notice given to persons with disabilities who were unaffiliated with these agencies.<sup>140</sup>

<sup>137</sup> *Ibid* at 25-27

<sup>136</sup> Ibid at 25

<sup>&</sup>lt;sup>138</sup> *Ibid* at 26

<sup>139</sup> *Ibid* at 30

<sup>&</sup>lt;sup>140</sup> Malacrida & Duguay, above at 26

The results of our research demonstrate that more work must be done to ensure universal design and accessibility in regulatory engagement processes. The barriers described above undermined the participation of persons with disabilities in regulation making. However, beyond that, they also impacted their dignity and implicitly conveyed that their needs were not important. Federal regulators must do more to ensure that persons with disabilities have an equal and meaningful opportunity to participate in regulation making.

### Recognition and Respect for Expertise

William Sherlaw and Hervé Hudebine state that persons with disabilities are entitled to "participatory parity" in the context of creating and implementing laws and policies.<sup>141</sup> This means that they should have "an equal possibility of voice".<sup>142</sup> Persons with disabilities, including those who are not affiliated with organizations, should feel as if they are "heard and that their needs are understood and taken into account" by policymakers.<sup>143</sup>

Some participants in the McGill study felt like they did not have a real opportunity to contribute during regulatory consultation meetings:

"A lot of people were not involved exactly in what was said, or again it was too dry for them to even bother to discuss that. There was some discussion, but it involved one or two people, and it's the same people would be the ones engaging in discussion. So, most of them were just listening." 144

Participants in the McGill study experienced consultation fatigue in part because of this "feeling that their voice was not heard" and "not feeling engaged (e.g. involved in decision-making)". <sup>145</sup> In their words:

"I think all it is, is a one-way street – that we're asked questions and then we give the answers and then we're not participating as equals at the decision-making table."

"They can listen to us instead of keep asking us for feedback. They are not listening. We know what we want." 146

<sup>141</sup> Sherlaw & Hudebine, above at 14, 17

<sup>142</sup> Ibid

<sup>&</sup>lt;sup>143</sup> *Ibid* at 14

<sup>144</sup> Movahed et al, above at 22

<sup>&</sup>lt;sup>145</sup> *Ibid* at 25

<sup>&</sup>lt;sup>146</sup> Ibid

To foster an open dialogue, governments and regulators may need to consider regulation development from the perspective of their stakeholders, including persons with disabilities. Raymond Lang and Ambrose Murangira, writing about policymaking in Africa, recognize that:

[o]ne of the most protracted and entrenched barriers to the implementation of human-rights-based disability policy and practice is that policy-makers on the one hand, and disabled people's organizations on the other, do not understand each other's 'world view'. 147

If regulators do not approach the engagement process with an understanding of and respect for the perspectives that persons with disabilities bring, they may undervalue their expertise. This may cause participants to feel that their feedback does not matter, and may contribute to consultation fatigue. However, academic scholarship, our qualitative research, and experiences with Ontario's standards development process all demonstrate that it is possible that taking steps to address this problem may facilitate a more productive conversation.

The McGill research findings demonstrate that regulators should be more receptive and open to the expertise and living experience of persons with disabilities. Participants expressed that regulators "did not seek their expertise enough" and they "felt that the consultation was not meant for people with lived experience". These frustrations may relate, at least in part, to questions and topics advanced by regulators that seemed unconnected to the living experience of persons with disabilities. Participants felt that their contributions were disregarded and viewed as less important:

"Individual briefs that were gone in and the individual voices, I am not totally convinced that those were necessarily heard and how much weight was given to them."

"That consultation has filtered out a lot of the voices of people with disabilities, and they've narrowed down to a number of points that they want to put forward in a consultation piece." 150

In this regard, it may be important for government stakeholders and staff to understand human rights principles and the significance of receiving the perspectives of persons with disabilities. For example, in Ontario, David Onley's independent review of the

<sup>&</sup>lt;sup>147</sup> Raymond Lang & Ambrose Murangira, "Barriers to the Inclusion of Disabled People and Disability Policy-Making in Seven African Countries" included in Jukka Kumpuvuori and Martin Scheinin, eds, *United Nations Convention on the Rights of Persons with Disabilities – Multidisciplinary Perspectives* (Helsinki, The Center for Human Rights of Persons with Disabilities in Finland, 2010) 159 at 174 <sup>148</sup> Movahed *et al.*, above at 20, 22

<sup>149</sup> *Ibid* at 9

<sup>150</sup> Movahed et al, above at 11

AODA received feedback recommending a more "collaborative conversation" as opposed to the adversarial negotiation structure that characterized many standard development committees. <sup>151</sup> One solution proposed to him was that the Ontario Human Rights Commission should provide human rights awareness training for government staff and committee members. <sup>152</sup>

As well, persons with disabilities can provide critical awareness-raising to enable staff involved in regulation development processes to better understand the living experiences of persons with disabilities, systemic ableism, accessibility, diversity within disability communities, and intersectional discrimination. This is consistent with the LCO's Framework, which requires that government staff implementing legal processes, such as the regulatory development process, "have the skills, knowledge and resources to treat those accessing it with respect, accommodate their needs, and ensure that they receive any supports [...] to which they are entitled." Similarly, our project partners recommended that staff from the regulator should receive training on working with persons with disabilities, and that this training should be given by persons with disabilities themselves.

Finally, to recognize the living experience and expertise of persons with disabilities, regulators must identify and address power imbalances that may occur in the context of regulatory development processes. The McGill study identified that "[p]ower relationships may surface in the process when government officials, who are used to public speaking, may be put side by side with individuals who are sharing personal details about their daily life experiences."<sup>155</sup>

These findings are consistent with the academic literature, which identifies power imbalances between governments and corporate charities, and persons with disabilities. In particular, government representatives command significant authority because of their role in designing and carrying out regulation making processes, and also in providing organizations of persons with disabilities with funding. In addition, government has access to greater informational, human and financial resources.

Power imbalances may be exacerbated by intersectional discrimination that participants experience. For example, persons with disabilities from racialized communities,

<sup>&</sup>lt;sup>151</sup> Onley, above at 29-30

<sup>152</sup> Ibid

<sup>153</sup> Scotland, First Minister's Advisory Group on Human Rights Leadership, "Recommendations for a new human rights framework to improve people's lives" (10 December, 2018) at 40, online: <a href="https://humanrightsleadership.scot/wp-content/uploads/2018/12/First-Ministers-Advisory-Group-on-Human-Rights-Leadership-Final-report-for-publication.pdf">https://humanrightsleadership.scot/wp-content/uploads/2018/12/First-Ministers-Advisory-Group-on-Human-Rights-Leadership-Final-report-for-publication.pdf</a>; General Comment No 7, above at para 60

<sup>&</sup>lt;sup>154</sup> Law Commission of Ontario, above at 19

<sup>&</sup>lt;sup>155</sup> Movahed *et al*, above at 12

<sup>&</sup>lt;sup>156</sup> Drake, above at 378

<sup>&</sup>lt;sup>157</sup> *Ibid* 

newcomer communities, gender diverse communities, and women with disabilities experience oppression and marginalization in unique ways. Regulators and consultation facilitators must be aware of and attentive to these experiences, and must take proactive steps to address any power imbalances that may result.

For these reasons, it is critical that facilitators ensure that everyone participating in a regulatory development meeting has an opportunity to contribute; that the conversation is not dominated by government or industry stakeholders; and that everyone's contributions are valued and respected.

### Recognizing the Connections between Living Experience and Accessibility Regulations

The McGill study and our project partners identified that often, background information provided by regulators and their framing of questions, meetings, and calls for written submissions did not recognize or highlight how the very technical subjects of a regulation related to the living experiences of persons with disabilities. This meant that persons with disabilities face the additional barriers of having to translate these technical topics to their more practical impacts, and then to justify the relevance of their input.

Participants in the McGill study described these barriers in the following way:

"The challenge of how you take your everyday experience and transfer that to a policy framework, I think that was a challenge for people."

"When you have a person who hasn't had experience in these processes at all, they bring to the table their lived experience with a certain authenticity and genuineness. It often brings sort of a real-life feel in the room. But it takes a person who has had some work with an organization to also articulate that in a way that helps for the advocacy outcome, so you need both." 158

Our project partners communicated similar concerns. They felt that regulators could more effectively convey how regulations might be relevant to, and might affect them in, their day to day lives. This would allow them to provide more helpful input and be more engaged in regulation development processes.

These findings are also reflected in the academic literature. Joseph Lane and Juan Rogers explain that someone who generates knowledge – in this case, the regulator – should "tailor their findings to the capacities and values of the target audiences to make the knowledge more absorbable" by people who do not have their technical expertise. 159

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<sup>&</sup>lt;sup>158</sup> Movahed *et al*, above at 11-12

<sup>&</sup>lt;sup>159</sup> Joseph Lane & Juan Rogers, "Engaging national organizations for knowledge

They explain that the recipients of this knowledge are more likely to understand and be interested if its content, format, and context are adapted with the audience in mind. 160

These research findings demonstrate that respect for the expertise of persons with disabilities extends beyond just an openness to receive personal stories and experiences. It also means that to engage persons with disabilities more meaningfully, regulators must consider their regulation from the perspective of persons with disabilities from the outset, and incorporate this perspective into the design of their background materials, meeting agendas, and questions they ask.

#### Compensation for Expertise

Regulators can also demonstrate respect for the expertise of persons with disabilities by providing compensation for their expertise, time and effort. The UN Committee on the Rights of Persons with Disabilities explains that states "should strengthen the capacity of organizations of persons with disabilities to participate in all phases of policymaking, by providing capacity-building and training on the human rights model of disability, including through independent funding." They also recommend that states "allocate funds for consultation" that are provided to diverse persons with disabilities, "including sustainable core institutional funding". 163

Failure to provide compensation is a significant barrier to participate in regulatory development. Lepofsky and Graham observe that persons with disabilities "are a large and substantially disadvantaged minority."<sup>164</sup> They are underrepresented in the workforce and in postsecondary education, but overrepresented among persons living in poverty.<sup>165</sup> They also face "chronic disadvantage [...] from decades of barriers that impede persons with disabilities from fully participating in society" and discriminatory attitudes and stereotyping "that equate disability and inability".<sup>166</sup> While some disability organizations have public funding, much of this funding is not the stable, "core" funding that the UN Committee recommends. This creates significant barriers for these

translation: Comparative case studies in knowledge value mapping" (2011) 6:106 Implementation Science 1 at 12

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<sup>160</sup> Ibid

<sup>&</sup>lt;sup>161</sup> General Comment No 7, above at para 60-61. This is consistent with the UN Committee's interpretation of articles 4(3) and 33(3) of the *CRPD* as requiring governments to provide representative organizations of persons with disabilities with core institutional funding and to ensure the autonomy of these organizations.

<sup>162</sup> *Ibid* at para 60

<sup>163</sup> *Ibid* at para 61

<sup>&</sup>lt;sup>164</sup> Lepofsky & Graham, above at 138

<sup>&</sup>lt;sup>165</sup> *Ibid* at 138-139

<sup>&</sup>lt;sup>166</sup> *Ibid* at 139

organizations to undertake and facilitate long-term capacity building with communities of persons with disabilities.

Our project partners have observed that it is difficult, and sometimes impossible, for under-resourced persons with disabilities and organizations to participate in regulatory development for little or no compensation. Furthermore, they raised concerns that without investments in community building, the more the demand for disability community input grows, the less capacity may exist within disability communities to fulfill these demands.

The McGill study reinforces that a lack of compensation and reimbursement for travel, accommodations and other expenses are significant barriers to meaningful participation of persons with disabilities in regulatory development.<sup>167</sup> These barriers were particularly concerning for persons with disabilities who were not affiliated with well-resourced organizations. Participants expressed that:

"We knew it [ACA public consultation] was important. I mean we all had to dig deep and within whatever we had. I mean people were selling things to just be able to participate ... I'll tell you the disability community is one of the hardest working communities because we have to just to survive."

[...]

"I'm volunteering. We're doing it for an organization that can't afford to pay, we're a consumer organization, so there are resource issues too. There is no way I could've done it on my own and if I wouldn't have been able to find six other people to help me; there's no way I could have done all of that alone." 168

The McGill study also reflects the importance of accounting for the individual circumstances and needs of participants. For example, failure to compensate persons with disabilities for expenses may disproportionately impact single parents who require childcare to attend in-person meetings. Some persons with disabilities require paid support persons, such as advisors for persons labelled with intellectual disabilities.

When considering compensation for participation in regulatory development processes, it is important that regulators structure these payments so that they do not jeopardize participants' income support benefits.<sup>171</sup>

<sup>&</sup>lt;sup>167</sup> Movahed et al, above at 12

<sup>&</sup>lt;sup>168</sup> *Ibid* at 24

<sup>&</sup>lt;sup>169</sup> *Ibid* at 12

<sup>&</sup>lt;sup>170</sup> *Ibid* at 29

<sup>&</sup>lt;sup>171</sup> *Ibid* at 12

The McGill researchers concluded that funding to "cover expenses related to accommodations, food, transportation, personal attendants (if needed), and childminding" would facilitate the participation of persons with disabilities. They also recommended that regulators should provide funding to organizations within disability communities that are traditionally underrepresented in regulation development processes. They concluded that funding was crucial to the ability of some participants to participate at all, as well as conveying a message that their time and expertise was valued:

"We have to feel that we are appreciated, we have to feel that the knowledge and experience that we are imparting are going to be used. So, this whole thing about not paying for services and time I think that needs to be addressed."

"Since we are very small number of staff, so to continuously engage civil society and not reimburse or provide an honorarium or just to assume that civil society has the capacity to dedicate this much mental effort into government consultation is a problem. But civil society gave a lot of time and effort, a lot of technical expertise, a lot of writing, a lot of drafting and rewriting and there is no money to do that outside of the projects." 174

Typically, many hours are required to review detailed, technical information, consult communities, participate in meetings and prepare written submissions. Providing compensation for the expertise and time spent by persons with disabilities could address the financial barriers to community capacity and participation evident in our research.

### Section 6(e): Diverse Participation and Recognition of Intersectional Experiences

Section 6(e) states that the *ACA* must be carried out in accordance with the principle that "laws, policies, programs, services and structures must take into account the disabilities of persons, the different ways that persons interact with their environments and the multiple and intersecting forms of marginalization and discrimination faced by persons". <sup>175</sup> In this regard, the UN Committee on the Rights of Persons with Disabilities' General Comment No 7 explains that law-making processes must involve organizations representing a wide diversity of persons with actual or perceived disabilities, as well as organizations representing persons with disabilities who experience intersectional

<sup>&</sup>lt;sup>172</sup> *Ibid* at 26

<sup>&</sup>lt;sup>173</sup> *Ibid* 

<sup>174</sup> Ibid

<sup>&</sup>lt;sup>175</sup> *ACA*, above, s 6(e)

discrimination.<sup>176</sup> Regulators must make best efforts to receive the perspectives of diverse communities of persons with disabilities.

#### Recruitment of Participants with Diverse Perspectives

Our research demonstrates the importance of recruiting persons with disabilities who bring diverse perspectives to regulation development. However, it also demonstrates that outreach and engagement efforts for regulation development processes are often under-inclusive.

Persons with disabilities have distinct living experiences that reflect multiple sites of discrimination. For example, "[n]early 2.1 million women (14.9%) [...] aged 15 or older reported having one or more disabilities that limited them in their daily activities in 2012."

177 In addition, 3.7% of Canadian children under the age of fifteen reported a disability in 2006.

178 The Native Women's Association of Canada also stated in 2018 that, "[u]pwards of 450,000 Indigenous people identify as having a disability, functional, or activity limitation, but it is unknown how many of those people are women, girls, or gender diverse because of inaccurate and insufficient data."

The DisAbled Women's Network of Canada explains that the living experience of persons with disabilities "is both complex and diverse and there is no monolithic experience of having a disability." They acknowledge that certain disabilities are less likely to be reflected in the literature and can be overlooked in research and policy development regarding persons with disabilities.

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<sup>&</sup>lt;sup>176</sup> General Comment No 7, above at para 50. This includes organizations representing children and women with disabilities, in addition to those representing a wide diversity of actual or perceived disabilities (para 28). To this end, the UN Committee has established criteria for representative organizations that participate in law-making processes, relating to their: goals to pursue the rights of persons with disabilities; employees and representatives being persons with disabilities; lack of affiliation with political parties and public authorities, and reflection of a diversity of backgrounds, whether they are focused on an actual or perceived disability or all persons with disabilities (para 11).

<sup>&</sup>lt;sup>177</sup> Amanda Burlock, "Women with Disabilities" (2017) Statistics Canada, online: <a href="https://www150.statcan.gc.ca/n1/pub/89-503-x/2015001/article/14695-eng.htm">https://www150.statcan.gc.ca/n1/pub/89-503-x/2015001/article/14695-eng.htm</a>

The Statistics Canada, "Participation and Activity Limitation Survey 2006: Families of Children with Disabilities in Canada" (2006), online: <a href="https://www150.statcan.gc.ca/n1/pub/89-628-x/89-628-x2008009-eng.htm">https://www150.statcan.gc.ca/n1/pub/89-628-x/89-628-x2008009-eng.htm</a>

<sup>&</sup>lt;sup>179</sup> Native Women's Association of Canada, "Accessibility and Disability for Indigenous Women, Girls, and Gender Diverse People" (2018) at 5, online: <a href="https://www.nwac.ca/wp-content/uploads/2018/05/Accessibility-Final-Report\_1.pdf">https://www.nwac.ca/wp-content/uploads/2018/05/Accessibility-Final-Report\_1.pdf</a>

<sup>&</sup>lt;sup>180</sup> DisAbled Women's Network of Canada, "More than a Footnote: A Research Report on Women and Girls with Disabilities in Canada" (2019) at 23, online:

https://dawncanada.net/media/uploads/page\_data/page-64/more\_than\_a\_footnote\_research\_report.pdf.

181 | Ibid at 17

Sherlaw and Hudebine assert that persons with disabilities and their representative organizations may take different views and approaches to the same issue.<sup>182</sup> Laverne Jacobs, Britney de Costa, and Victoria Cino also observe that the distinct living experiences of persons with disabilities are informed by other personal characteristics, such as race, gender, sexual orientation and others.<sup>183</sup> If certain groups or persons with disabilities cannot participate in the regulatory development process, this could significantly limit the diversity of perspectives available to policymakers.

The under-inclusive nature of consultations was raised as an issue in the Ontario accessibility standards development process, as well as in jurisdictions outside Canada. 184 Charles Beer's legislative review of the *AODA* described concerns that persons with non-evident disabilities, such as mental health or learning disabilities, were underrepresented in Ontario's standards development process. 185 This problem persisted, according to David Onley, who conducted a subsequent review of the *AODA* and recommended that the Ontario government ensure cross-disability representation on standards development committees, including persons with evident, non-evident and episodic disabilities and a range of ages. 186 Academic literature in the United Kingdom also demonstrates that barriers to participation may mean persons with disabilities affiliated with smaller organizations feel overlooked. 187

The McGill study reinforces these findings from the legal research. In particular, Indigenous persons with disabilities who live on reserves and others who live in remote areas face additional barriers to participation. Research participants explained that:

"The Indigenous person with two or three disabling conditions living on a remote reserve does not have an opportunity to do the government consultations, does not have adequate opportunity to have input and participate fully. So that's just an example of the people who have disabilities that are not the outspoken ones, who may not have access to a computer, who may not have that level of capacity to actually reply to an online survey and are not comfortable with using IT and may not have access to."

<sup>&</sup>lt;sup>182</sup> Sherlaw & Hudebine, above at 15

<sup>&</sup>lt;sup>183</sup> Laverne Jacobs, Britney de Costa & Victoria Cino, "The Accessibility for Manitobans Act: Ambitions and Achievements in Antidiscrimination and Citizen Participation" (2016) 5:4 Canadian Journal of Disability Studies 1 at 10

<sup>&</sup>lt;sup>184</sup> Under-inclusive representation of persons with disabilities is also an issue outside of Canada. In a research study conducted in Iceland, no organizations meeting the *CRPD* definition of representative were included in the working group for legislation regarding persons with disabilities, and for a period of time, no persons with disabilities were included at all: Löve *et al*, above at 8, 11

<sup>&</sup>lt;sup>185</sup> Beer, above

<sup>&</sup>lt;sup>186</sup> Onley, above at 29

<sup>&</sup>lt;sup>187</sup> Graeme Baxter, "The Best Laid Schemes? The Provision and Accessibility of Government Consultation in the UK" (2010) 60 Libri 253 at 265

In addition, participants in the McGill study highlighted the barriers to participation in regulation development for children, youth and their families, including lack of childcare, child-friendly information, and lack of "safe spaces" for children and youth with disabilities to participate.<sup>188</sup>

Participants in the McGill research also explained that groups such as newcomers to Canada with disabilities, LGBTQIA2S+ persons with disabilities, and others were also underrepresented in regulation making. They attributed this to language barriers, lack of financial resources, lack of knowledge about regulations in development, and lack of opportunities to participate. 190

#### Proactive, Transparent and Accessible Recruitment

Regulators should take proactive measures to reach groups that may face particular barriers to participation, such as persons labelled with intellectual disabilities or persons with communication disabilities.<sup>191</sup> It is not enough to receive feedback from a limited group of participants or participants who have contributed to regulation development processes in the past. Our research demonstrates that many persons with disabilities, especially those who are unaffiliated with large organizations, are not aware of regulatory consultations and are not engaged by outreach methods currently employed by regulators.

For example, those with particular types of disabilities or urban dwellers may be more likely to take part in policymaking. The McGill research demonstrates that in-person consultations are often held in large cities and may exclude people outside of urban centres:

"A real bias that happens with a lot of these things is, it tends to focus on urban, the urban experience of people with disabilities."

[...]

"I remember the disability group was consulting on their own in locations where the federal government had not been in order to try and provide the feedback

<sup>188</sup> Movahed et al, above at 18

<sup>&</sup>lt;sup>189</sup> *Ibid* at 19

<sup>&</sup>lt;sup>190</sup> *Ibid* 

<sup>191</sup> Sherlaw & Hudebine, above at 15-16; General Comment No 7, above at para 54

<sup>&</sup>lt;sup>192</sup> Lang & Murangira, above, make these observations about participation in policymaking in African countries at 170-171, 180-183

with people with disabilities that may not have to go to an in-person public session." 193

Participants suggested that regulators should provide funding for transportation and hold meetings in more remote communities and other locations where underrepresented groups would be more likely to attend:

"They [the government] have to go to the community to do the consultation and provide transportation allowance because not everyone has technology that if you move everything to technical and surveys and sort of the easy way to do consultation and just throwing it up online and do the survey." 194

"But if you really want to have a full picture of what people with a broad range of disabilities face in this country, you've gotta get on your knees and talk with them in their own space. So, for example, what about people with disabilities in prisons, what about people with disabilities who are homeless?" 195

Our project partners raised concerns that persons with disabilities who are not affiliated with a non-governmental organization or community organization are often left out of regulation development processes. These concerns were also supported by the findings of the McGill researchers, who concluded that there are "the same people at meetings all the time" and that "information about consultations was not advertised widely or disseminated but stayed within the same group of people." <sup>197</sup>

In particular, people outside of larger organizations are unlikely to be aware of consultations about regulations. Participants in the McGill study said that:

"The majority of them don't even know this is happening, and they don't know how to contribute, and they don't have the knowledge background to contribute. I think that there is so much untapped potential in educating people and then getting their voices heard." 198

Similar findings were reached by studies done in Alberta and Scotland. <sup>199</sup> These findings were also confirmed by our project partners, who emphasized the importance

<sup>196</sup> *Ibid* 

<sup>&</sup>lt;sup>193</sup> Movahed et al, above at 19, also go to: 14. Also go to: Malacrida & Duguay, above at 25-26

<sup>194</sup> Movahed et al, above at 19

<sup>&</sup>lt;sup>195</sup> *Ibid* at 21

<sup>197</sup> Ibid at 22

<sup>&</sup>lt;sup>198</sup> *Ibid* 

<sup>&</sup>lt;sup>199</sup> Malacrida and Duguay concluded that many persons with disabilities were unaware of the Alberta government's consultations or found out about them at the last minute when it was too late to participate: Malacrida & Duguay, above at 26. A study regarding government consultations in Scotland also demonstrates that many persons with disabilities did not know about consultations about government

of more proactive steps by regulators to engage participants. These research findings demonstrate that underinclusive outreach by regulators creates barriers for persons with disabilities who are not aware of consultations and therefore cannot participate.

Consequently, regulators must make particular efforts to advertise their engagement processes to persons with disabilities who have not participated in regulation development before, particularly those in underrepresented groups. The McGill study concluded that regulators should "improve their outreach strategies", identifying newsletters, social media, and the dissemination of information through the websites of larger organizations.<sup>200</sup> In addition, persons from underrepresented groups could be hired to improve outreach efforts by regulators. The academic literature supports the "internal" influence that government staff with disabilities can have to improve accessibility to policy making based on their living experience and their access to government processes and decision-making. 201

Another barrier that ARCH observed during the course of this project was the use of closed meetings as a method of consultation. Closed meetings are by invitation only and are not publicly known. Generally, the information and input received at closed meetings is not made publicly available, nor is it known how this input influences the regulation being developed. Closed meetings may be an attractive option for government and regulators because they can exert a high degree of control over who attends these meetings, what perspectives are provided, and what topics are discussed. Indeed, during the course of this project closed consultation meetings were held by federal regulators responsible for developing accessibility regulations and by Accessibility Standards Canada, the body charged with developing federal accessibility standards.

However, closed consultation meetings do not accord with principles of substantive equality, the ACA's section 6(f) that people with disabilities must be involved in regulation development processes, or the ACA's section 6(e) principle recognizing diversity of experiences of disability communities. Often it is persons with disabilities who are regularly involved in policy discussions with government who are invited to closed consultations. Underrepresented persons with disabilities are rarely invited. Closed consultations do not encourage inclusion and participation, instead they are exclusive. They do not promote transparency and accountability in regulation development process, instead they are secretive. For these reasons they have the effect of undermining trust and creating additional barriers to regulatory development.

policymaking: Graeme Baxter, Rita Marcella & Laura Illingworth, "Organizational information behaviour in the public consultation process in Scotland" (2010) 15:4 Information Research 1 at 6-7

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<sup>&</sup>lt;sup>200</sup> Movahed et al, above at 30

<sup>&</sup>lt;sup>201</sup> Drake, above at 380-381

Our research shows that regulators should be proactive and transparent to ensure that underrepresented groups are recruited during regulation development. The input that members of these groups can provide is important for regulators to receive in drafting regulations that respond to the practical realities of all persons with disabilities.

#### Section 6(g): Achieving the Highest Level of Accessibility

Section 6(g) of the *ACA* states that it must be carried out in accordance with the principle that "the development and revision of accessibility standards and the making of regulations must be done with the objective of achieving the highest level of accessibility for persons with disabilities." Whether the *ACA* and its accessibility regulations and standards actually achieve the highest level of accessibility is something that should be measured against the feedback and recommendations from persons with disabilities themselves. Section 6(g) sets a standard to which the *ACA* can be held accountable. This principle of accountability can be readily applied to the regulation development process. Regulators should be transparent about how input from persons with disabilities is incorporated into draft regulations, why they choose not to adopt some recommendations at all, and how draft regulations will meet the highest level of accessibility.

#### Effective Follow-Up Post-Engagement Processes

Our research demonstrates that a lack of effective follow-up from regulators after people with disabilities participate in regulatory development processes is a barrier to meaningful participation. Persons with disabilities indicated their desire for regulators to follow-up after their participation in regulation development to acknowledge their participation and explain in concrete terms how their input was considered and used by the regulator.

The McGill researchers concluded that participants in regulation development would appreciate an acknowledgment of their work after an engagement process has concluded.<sup>203</sup> Participants stated that they are less likely to experience consultation fatigue if their contributions are recognized:

"If you just ask a bunch of questions and then just leave, then you are going to tucker people out. But if you come back and say, 'Hey this is what happened,

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<sup>&</sup>lt;sup>202</sup> *ACA*, above s 6(g)

<sup>&</sup>lt;sup>203</sup> Movahed et al, above at 30

thanks for your efforts', or things like that, that go far because it feels like you're connecting with people."204

Another barrier to effective participation in the regulatory development process relates to lack of communication by regulators about how they consider and use feedback they receive. The participants in the McGill study emphasized their frustration with the lack of response after consultations concluded. They did not know what happened to their input and questioned whether it would be helpful to continue providing it:

"Probably for the first time in Canada cross-disability groups were in the same room together and that was a lot because mostly we don't ever get together. It's always on a conference call, it's always on a list, but we're not physically in the room to build that network of support and that understanding between each other. And that was probably from an outcome of that that was pretty cool. And also that the minister herself was very accessible at the time. She was out there to listen, to be involved ... Then it was like everybody's up there going 'what's next', and there was no follow-up to take all that energy."

"It's hard to continue to get people to have input and provide input when they don't see the follow-up or the results."205

Participants in the McGill study wanted information about concrete use of their input by regulators.<sup>206</sup> Our project partners expressed that they also wished to know how regulators considered their feedback and why they decided not to adopt certain recommendations.

Without any follow-up by the regulator with information about how they used the information received from persons with disabilities during regulation development, participants in the McGill study were left wondering whether their feedback led to any tangible results. One participant expressed that:

"They get fed up because they don't see results, or they don't understand what the results are."207

While some participants received "[l]engthy reports in technical language" that they did not find meaningful, more often they received no information at all.<sup>208</sup> The "What We Heard" documents that regulators typically produce after regulatory consultations were not helpful because they did not provide any information about how the regulator was going to use the feedback and why:

<sup>&</sup>lt;sup>204</sup> Ibid

<sup>&</sup>lt;sup>205</sup> *Ibid* at 22

<sup>&</sup>lt;sup>206</sup> *Ibid* at 29

<sup>&</sup>lt;sup>207</sup> *Ibid* at 25

<sup>&</sup>lt;sup>208</sup> *Ibid* at 29

"Well it was a massive document and it was written in a way where I wasn't sure exactly what the benefit of that was. For instance, the need for sign language to be included and to be recognized as an official language in Canada. So that concept was made loud and clear, but it wasn't clear in the summary document if they were going to move in that direction."<sup>209</sup>

These findings are reflected in the experiences of others. In Manitoba, Theresa Pruden recommended that committee members should be informed about what happens to their proposed standard by creating an information feedback loop.<sup>210</sup> Pruden also suggested that work prepared by committees be permanently posted online to promote transparency.<sup>211</sup> A study in Scotland demonstrates similar trends, explaining that "[t]he most frequent criticism aimed at government consultative processes in the UK concerns a lack of feedback to respondents on the results of consultations."<sup>212</sup>

The desire of people with disabilities to receive more robust, concrete feedback by regulators is consistent with the LCO's recommendation that government should document their analysis and decisions throughout the law-making process.<sup>213</sup> More effective feedback could mean that regulators explain how the input of persons with disabilities was used to inform the regulatory text or any changes to the regulation, and why certain feedback was not found to be helpful or not included in changes to the regulation.

Follow-up by regulators may be informed by the academic literature on knowledge mobilization or translation. This literature can help to identify concrete and practical uses for the information learned during engagement processes. Rather than simply reporting back the information they received, regulators should explain the decisions they made regarding the regulation's goals, language, and approaches and why they accepted or rejected the feedback on each.

The Social Sciences and Humanities Research Council defines knowledge mobilization as "an umbrella term encompassing a wide range of activities relating to the production and use of research results, including knowledge synthesis, dissemination, transfer, exchange, and co-creation or co-production by researchers and knowledge users."<sup>214</sup>

<sup>210</sup> Pruden, above at 18

<sup>212</sup> Baxter et al, above at 9

<sup>&</sup>lt;sup>209</sup> *Ibid* at 30

<sup>&</sup>lt;sup>211</sup> Ibid

<sup>&</sup>lt;sup>213</sup> Law Commission of Ontario, above at 116

<sup>&</sup>lt;sup>214</sup> Social Sciences and Humanities Research Council, "Guidelines for Effective Knowledge Mobilization", online: <a href="https://www.sshrc-crsh.gc.ca/funding-financement/policies-politiques/knowledge\_mobilisation-mobilisation\_des\_connaissances-eng.aspx">https://www.sshrc-crsh.gc.ca/funding-financement/policies-politiques/knowledge\_mobilisation-mobilisation\_des\_connaissances-eng.aspx</a>. Similarly, the Canadian Institutes of Health Research defines knowledge translation as "a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve the health of Canadians, provide more

Bayley *et al* describe the gap between knowledge generation and use as the "know-do gap".<sup>215</sup> They outline a knowledge competency mobilization framework that identifies competencies that will assist knowledge brokers in bridging this gap.<sup>216</sup> These competencies include: communication; managing partners and relationships; training and capacity building; understanding, creating and using knowledge translation tools; and evaluating knowledge translation.<sup>217</sup> Knowledge translation tools might include visual representations, learning series and resource collections, and web-based collaborative technology such as social media.<sup>218</sup>

# Part V: Relating this Project to Other Work to Make Accessibility Regulations Real for Persons with Disabilities

While ARCH conducted our Meaningful Participation of Persons with Disabilities in Regulation Making Project, a number of other projects relating to the *ACA* and its regulations were also being carried out. This section of the report addresses how the work and findings of Employment and Social Development Canada's Innovation Lab support and extend the findings of ARCH's project.

Employment and Social Development Canada's Innovation Lab conducted a project entitled *Accessible Canada Act* in Application. Through this project the Innovation Lab held a series of workshops to inform guidance documents intended to accompany the Government of Canada's *ACA* regulations. The Innovation Lab's methods implemented and tested some of the strategies that are highlighted in ARCH's research. In this way, the Innovation Lab's project demonstrated that certain approaches to remove barriers are effective and may be feasible within or alongside existing regulation development processes. It is important to understand that ARCH's analysis of the Innovation Lab's project is based on our research results but we have not received feedback from persons with disabilities about how they experienced these workshops.

First, the Innovation Lab conducted interviews with persons with disabilities to inform the design of its methods and research activities.<sup>219</sup> This is consistent with ARCH's

effective health services and products and strengthen the health care system: Canadian Institutes of Health Research, "Guide to Knowledge Translation Planning at CIHR: Integrated and End-of-Grant Approaches", online: https://cihr-irsc.gc.ca/e/45321.html

<sup>&</sup>lt;sup>215</sup> Julie Bayley, David Phipps, Monica Batac & Ed Stevens, "Development of a framework for knowledge mobilisation and impact competencies" (2008) 14:4 Evidence & Policy 725

<sup>&</sup>lt;sup>216</sup> Bayley et al at Table 4

<sup>&</sup>lt;sup>217</sup> Ibid

<sup>&</sup>lt;sup>218</sup> Bayley *et al* at Table 4

<sup>&</sup>lt;sup>219</sup> Employment and Social Development Canada, Innovation Lab, "*Accessible Canada Act* in Application Draft Project Report" (September 2020) at 19, 21

research findings that regulators should involve persons with disabilities early in regulation development, and should create engagement strategies with the input, circumstances and needs of persons with disabilities in mind.

Second, the Innovation Lab's use of interactive co-creation workshops demonstrates collaboration and two-way dialogue that could lead to more meaningful regulation development processes. This is consistent with ARCH's findings from the legal research, the project partners and the McGill study that persons with disabilities would like more engagement during consultations that allows a conversation to take place. Some of the strategies employed by the Innovation Lab, such as making changes to its workshops based on feedback from participants, facilitating conversations, and designing small working groups, are all consistent with ARCH's research and could have the potential to foster an active and meaningful conversation. The response rate of only 10% to the Innovation Lab's written survey also may support ARCH's findings that one-way feedback processes are often less meaningful.

Third, the Innovation Lab's goal to engage persons with disabilities who do not usually participate in regulation development is also supported by ARCH's research.<sup>223</sup> The Innovation Lab did not explain in detail how participants were recruited, only stating that it "collaborated with regional co-facilitators to tap into their networks" and "targeted community organizations to broker introductions to their clientele/members".<sup>224</sup> However, to the extent that the Innovation Lab engaged persons with disabilities to assist them in recruitment, this approach is supported by ARCH's research.

Finally, the Innovation Lab compensated participants and paid their travel expenses. These practices also accord with ARCH's research.<sup>225</sup> This is consistent with ARCH's findings that persons with disabilities experience significant financial barriers to participation. Compensation of persons with disabilities for their expertise in the codevelopment of guidance documents both respects their dignity and promotes capacity building.

In conducting its work to recommend prototypes for guidance documents, the Innovation Lab has effectively provided "proof of concept" for some of the recommendations that are described in the next section. When reviewing our recommendations, regulators should be mindful that some of these steps have already been successfully tried and implemented.

<sup>&</sup>lt;sup>220</sup> *Ibid* at 19-20, 22-23

<sup>&</sup>lt;sup>221</sup> *Ibid* at 22-23

<sup>&</sup>lt;sup>222</sup> Ibid at 23

<sup>&</sup>lt;sup>223</sup> *Ibid* at 22

<sup>&</sup>lt;sup>224</sup> Ibid

<sup>&</sup>lt;sup>225</sup> Ibid

# Part VI: Recommendations for Regulators

Based on our legal research, the McGill research study, and feedback from our project partners, ARCH has developed the following recommendations for the Government of Canada, the Canadian Transportation Agency and the CRTC. These recommendations advance concrete ideas to make *ACA* regulatory development processes more accessible, participatory and meaningful for people with disabilities.

Overall, our research found that persons with disabilities experience multiple barriers when participating in existing regulatory development processes. Existing processes are highly technical, and due to systemic ableism and intersectional discrimination persons with disabilities often lack the necessary knowledge, skills and supports to participate effectively. Our research also found that many persons with disabilities are excluded from existing regulatory development processes altogether. Given our research findings, it follows that significant changes are needed to make regulatory development processes more participatory, inclusive and meaningful for persons with disabilities. However, during our meetings with regulators, they were clear that existing regulatory development processes are entrenched and will be difficult to change, at least in the short term. To address this constraint, we have taken a pragmatic approach and divided our recommendations into three categories:

- Recommendations that can be implemented within existing regulatory development processes;
- Recommendations for new processes that could happen alongside existing regulatory development processes; and
- Recommendations for changing existing regulatory development processes.

Within each category, the recommendations are interrelated and are intended to be implemented as a suite. If implemented, the recommendations in the first two categories would enhance the accessibility of existing regulatory development processes and make them more meaningful for persons with disabilities. However, given the inherent complexity and structure of existing regulatory development processes, barriers would remain and some persons with disabilities would almost certainly continue to be excluded. The recommendations in the third category are intended as a starting point for envisioning an entirely new way to conduct regulatory development, implementing the principles of substantive equality and the section 6 principles of the *ACA*.

# Recommendations that could be implemented within existing regulatory development processes

#### 1. Before Conducting Regulatory Consultations and Engagement Sessions

#### (i) One Common Accessible Website

Each regulator should post all information about *ACA* regulatory consultations on one common, accessible website. Some regulators already post information about their regulatory consultations on their own websites, but there is a need to improve accessibility and dissemination of their existing webpage.

This recommendation responds to the research findings in the McGill study and feedback from our project partners that many persons with disabilities do not know that regulatory consultations are happening, and even if they do know, they do not have the knowledge of regulatory development processes needed to participate. This recommendation also relates to our findings that accessibility barriers still exist within some regulatory consultations. The development of one, common webpage will not alone address all the barriers identified in our research findings, rather it must be implemented along with the other recommendations in this category.

The common webpage should include the following information in a visible and quick access space:

- A contact person to answer questions about the regulation development process generally and to arrange for disability accommodations during engagement processes to ensure that they are accessible;
- status updates regarding regulations under development; and
- documents related to the consultation (background information, preparation materials where pertinent) in accessible formats.

This website should employ universal design and meet the highest standards of web accessibility. Text should be in plain language. The website should also include videos in American Sign Language and langue des signes Québécoise to provide summaries of the most important information, and to explain how to request other information in sign language as required.

The designated contact person should be trained to interact with persons with disabilities and knowledgeable about how to arrange accommodations and supports

when required. For example, the contact person must know how to provide information in plain language, know how to arrange access to Communication Access Real Time Translation (CART) or other alternative audio communication, be able to generate documents in Braille, large print and other accessible formats upon request, and know how to communicate with persons who have a broad range of speech and language disabilities and who may communicate using unclear speech, a communication board, or a device.

A secondary page within this website could link to resources that could support capacity building in disabilities communities, as recommended by our research. These resources might include:

- accessible, plain language general resources about what each of the regulators do;
- information about what kinds of accessibility regulations each of the regulators has the power to make;
- information about how regulation development processes work and what stages involve persons with disabilities; and
- how persons with disabilities can participate in regulation development processes.

The promotion of this website is important as well. All social media posts should link to this main website. The regulators could also improve their outreach strategies by asking disability organizations and disabled persons organizations to post information about regulations development opportunities on their websites and/or in their newsletters. This may assist in efforts to reach smaller organizations and persons with disabilities who are not affiliated with any organizations.

ARCH notes that the Accessibility in Action project, currently underway, may provide opportunities to implement this recommendation through the development of an accessible online platform to facilitate effective engagement in the implementation of the *ACA*.

#### (ii) Mailing list to provide information about regulation development

A mailing list could direct persons with disabilities to the common accessible website at relevant times and provide regular information relevant to regulations under development. Currently, to learn about regulations in development and opportunities to participate, persons with disabilities need to regularly check the Canada Gazette as well

as websites of each regulator that makes accessibility regulations. This raises significant accessibility barriers, especially for persons with disabilities who are not connected to large organizations. A mailing list would alleviate some of these barriers. ARCH and our project partners emphasize that not all persons with disabilities have access to computers or the Internet, and some people with disabilities need supports to use their computer. While the mailing list would be mainly by e-mail, regulators must be also be able to send people notices and information by regular mail, in accessible formats as needed, and by automated phone messages.

Interested persons could sign up to this mailing list to receive emails with notices of consultations and updates on the regulatory development process. Mailing list updates could include information in plain language about:

- plans for upcoming consultations;
- notices of consultations;
- funding opportunities;
- job openings relating to consultation processes; and
- information about any delays or changes in plans.

This mailing list would serve four functions that are highlighted by our research. First, it would allow for more continuous participation in regulation development, consistent with the UN Committee's interpretation of the *CRPD*. Second, it would improve transparency in the regulation development process, as recommended by participants in the McGill study, our project partners, and the independent reviewers of provincial accessibility standards development processes. Giving this information could build trust and allow smaller organizations or people who are not affiliated with organizations to have access to more of the same information that larger organizations have. Third, it could help to ensure that more persons with disabilities are aware of ongoing accessibility regulation development processes. Fourth, this mailing list could direct persons with disabilities to background materials and notices of consultations well in advance, consistent with feedback from the McGill study and our project partners.

#### (iii) Coordination between regulators with respect to the timing of consultations

The McGill research study demonstrated that when multiple consultations were held close together in time, this contributed to consultation fatigue among people with disabilities, and created barriers that prevented some people with disabilities from participating. Regulators should coordinate to hold consultations on a similar theme together to avoid unnecessary repetition and time spent. Failing this, they should hold consultations months apart if the same stakeholders ought to participate.

Regulators should give disability communities advanced notice before consultations are held, so that persons with disabilities can plan how to use their limited financial and human resources. Regulators should also consider allowing persons with disabilities more time to provide input or to prepare for consultation meetings. Providing more time from the outset is consistent with principles of universal design, and means that participants who would require this as a disability-related accommodation do not need to request it.

#### (iv) Information about how to request laws and regulations in alternate formats

To participate effectively in regulatory development, persons with disabilities need to be able to review the enabling legislation for the proposed regulation that is being developed. They may also need to review other laws and regulations that may be impacted by the proposed new regulation. As well, finalized accessibility regulations should be readily available in accessible formats so that persons with disabilities can refer to them and rely on them when they are implemented. Currently, official versions of federal laws and regulations are available on the Government of Canada's website, the free online legal resource CanLII, and in the Canada Gazette. However, there is no process via the Government of Canada's website to request alternate accessible versions of federal laws and regulations. This may prevent some persons with disabilities from accessing these important resources, and is consistent with the findings of the McGill study and observations of our project partners that information relating to regulation development is not always available in accessible formats.

The Government of Canada should outline in plain language, in American Sign Language and langue des signes Québécoise how to request copies of laws and regulations in alternate formats on its website. It should also designate a contact person who could be reached by telephone to make requests for paper copies or other alternate formats.

#### (v) Proactive recruitment of underrepresented persons with disabilities

Based on the collection and analysis of anonymized, disaggregated demographic data (described below), regulators should take active steps to reach groups who are missing or underrepresented in regulatory consultations. Regulators must engage underrepresented groups, learn about their circumstances and needs, and build ongoing relationships to engage these groups more regularly in regulation development. The information that regulators could learn from these communities about the particular barriers they face could inform the content of accessibility regulations and the design of consultations and accommodations that are offered.

Regulators should develop targeted outreach plans in an effort to include underrepresented communities in the next regulatory consultation. Regulators may hire persons with disabilities to assist them to develop and implement outreach efforts. To reach some communities, regulators may need to develop partnerships with local communities, organize additional meetings and/or meet people in their community spaces (whether virtual or in-person).

During the Innovation Lab's project, interactive co-creation workshops were specifically aimed at engaging persons with disabilities who had not participated in regulation development before. Lessons learned from this part of the project may help to inform the approaches that regulators consider for recruitment and outreach activities.

#### (vi) Universal design and accommodations

While some regulators already take steps to make their consultations accessible, full accessibility is paramount and the McGill research study demonstrates that additional steps are needed. Regulators must employ universal design when organizing regulatory consultations and engagement processes. These processes must be designed to be fully accessible at the outset, rather than accessibility being added on after the process is already underway. Key accommodations identified in our research that should be built-in to engagement processes include:

- Fully accessible venues (including built environment accessibility and wayfinding accessibility) and onsite attendants and support staff for in-person meetings;
- Accessible language options such as CART or real time captioning, American Sign Language, langue des signes Québécoise, Indigenous sign language, intervenors for deaf-blind persons, and communication assistance for people who have speech and language disabilities;
- Accessible websites and documents (electronic and hard copy formats), including plain language and accessible formats such as large print, Braille, and accessible electronic formats;
- Onsite staff to assist with communication, notetaking, recording and/or scribing;
- Multiple accessible options for providing input, including by mail (for persons with disabilities who do not have access to the Internet), video, or American Sign Language or langue des signes Québécoise video;
- Accessible platforms and practices for teleconferences and virtual meetings (for example, a virtual platform that includes a chat box for comments that are

monitored and read by staff may be more accessible for some persons with communication disabilities); and

 Enough time for preparation prior to consultation and for engagement during the consultation. Persons with communication disabilities, Deaf persons and other people with disabilities may require additional time to communicate.

Designing a consultation or engagement process to be as universally accessible as possible does not alleviate the legal requirement for regulators to accommodate the disability-related needs of individual persons with disabilities. Regulators should clearly indicate that accommodations are available, provide a non-exhaustive list of concrete examples of accommodations that can be requested, and explain how to request these accommodations, and any others that a person may require. For example, in their notice of consultation some regulators already explain that accessible formats of documents may be available. In this notice, regulators should provide the name and contact information of a specific staff person who is responsible for arranging accommodations. This recommendation comes from some of the experiences described in the McGill study and from our project partners, which demonstrate the importance of facilitating conversations about accommodations well in advance of meetings or deadlines. If participants sign up for a meeting, they could also receive an e-mail outlining the accommodations that are already available and providing the contact information of a person who can answer accommodation requests.

Regulators should also provide more time to prepare for consultation meetings or draft written submissions when persons with disabilities require it. More time may be required because of disability-related accommodation needs, or because a person needs time to reach out to their community to facilitate community input into the consultation. In some cases, before sending information about the regulation to their communities, persons with disabilities may need additional time to put the information into accessible forms such as sign language, plain language or accessible electronic formats. This recommendation flows directly from the experiences of the McGill study participants and our project partners.

#### (vii) Regulatory consultations in multiple modes

Our research demonstrates that a one-size fits all approach is not suitable for effective engagement of diverse persons with disabilities. Instead, regulators should conduct regulatory consultations in multiple modes to make them as accessible as possible, to receive diverse perspectives, to overcome barriers such as arranging accessible travel, and to address (as much as possible) the realities of living in remote areas. Multiple modes for regulatory consultations include:

- face-to-face meetings;
- teleconferences;
- town hall meetings;
- online surveys;
- written submissions;
- · virtual meetings; and
- participation through social media (such as online surveys, Twitter live, and Facebook discussion groups).

Our research demonstrates that two-way processes in small groups with the opportunity for dialogue between persons with disabilities and regulators on specific topics are most likely to be meaningful for persons with disabilities. The Innovation Lab's workshops, which emphasized interactive conversations, collaboration, and dialogue, show that engagement on regulations in this way can be conducted successfully.

Where one-way processes (i.e., no opportunity for interaction during the consultation), such as town hall meetings or online surveys, are used, regulators should provide opportunities for persons with disabilities to follow-up to ask questions. This relates to the findings from the McGill study, the legal research, and the input from project partners that engagement processes that allow for dialogue are more meaningful and inclusive.

#### (viii) Accessible background information provided well in advance

The McGill study, our project partners, and the independent reviews of standards development in Ontario demonstrated the importance of accessible background information and materials to educate persons with disabilities about regulation making and the particular regulation being developed. Persons with disabilities need this information in order to relate their living experience to the technical topics of an accessibility regulation and give helpful feedback.

These background materials should be developed with input from persons with disabilities. From the beginning, they should be created with content relevant to their living experiences and in accessible languages and formats.

With respect to the content, background information should contain the key points about the goals and approaches of the regulation including:

What new legal requirements it creates;

- How it may impact or interact with existing legislation and regulations that are particularly relevant for persons with disabilities;
- Concrete examples that relate to the living experience of persons with disabilities
  to show how the regulation may make a difference in their day-to-day lives.
   Framing background information in ways that relate living experience of persons
  with disabilities to the proposed regulation will help people understand how the
  proposed regulation will impact them and/or their communities, and will enable
  them to provide specific, relevant feedback to regulators; and
- Information about what input the regulator is seeking, and what topics are outside
  of the scope of the consultation or have already been decided.

In addition, background information must be worded, formatted and disseminated appropriately. Our research demonstrates that it should:

- Be provided at least 3 weeks in advance of the consultation meeting or deadline
  to give persons with disabilities time to translate and relay this information to their
  communities. Providing background information as soon as it is available, even
  more than 3 weeks in advance, would be ideal;
- Present the key points first, including a clear outline of the agenda for a consultation meeting, the process for the consultation, the goals of the consultation, and what is expected from the participants;
- Be available in American Sign Language, langue des signes Québécoise, Indigenous sign language, plain language, and other accessible formats, e.g. readable by screen-reader software, Braille, large print and others. Note that although PDF documents can be made fully accessible, this is difficult to do properly and persons who are blind or have vision disabilities report that PDF is generally not accessible for them. Therefore, PDF should be avoided;
- Explain technical and complicated ideas as simply and concisely as possible, employing universal design approaches and plain language; and
- Ask consultation questions that relate to the living experience of persons with disabilities, or create opportunities for persons with disabilities to relate their living experiences to the consultation.

#### (ix) Persons with disabilities hired as paid knowledge brokers

Many of the previous recommendations focused on regulators creating background materials, designing consultations, arranging accommodations, and providing facilitation in ways that are accessible and meaningful to persons with disabilities. To accomplish these tasks in a way that is most likely to respond to the circumstances and needs of persons with disabilities, regulators should hire persons with disabilities themselves to provide their expertise and guidance to regulatory development processes.

As described above, our project partners and the McGill study emphasized making changes to regulation development in collaboration with persons with disabilities and the need to pay persons with disabilities for their time and expertise as participants in regulatory development. However, during our meetings with regulators, they were clear that paying persons with disabilities to participate in regulatory consultations is not part of current regulation development processes. They were also clear that it is highly unlikely that this will change.

However, persons with disabilities could be hired as "knowledge brokers" to provide assistance to regulators in the design and implementation of regulatory consultation processes. This should be a paid role as a consultant or employee. As knowledge brokers, persons with disabilities could:

- Act as facilitators during consultation meetings;
- Create or contribute to accessible background information about the regulation or plain language versions of technical documents;
- Develop questions for consultations that focus on living experience and personal stories of persons with disabilities and relate those to the regulation;
- Develop outreach strategies for persons with disabilities who have not historically participated in consultations and/or would not necessarily know about the consultation otherwise. It is important that these outreach strategies be cocreated with members of these underrepresented communities to ensure that they are meaningful and culturally sensitive;
- Provide training for other persons with disabilities who will participate in consultations about regulation development;
- Train government or regulator staff, who will be present at the consultation and reviewing feedback from it, about the living experience of persons with disabilities and human rights principles relevant to persons with disabilities. This training

could also explain that, for some persons with disabilities, relating personal stories may be traumatizing, and that government or regulator staff must engage with empathy and respect. This training should be given whenever new staff are hired or transferred into roles that involve participating in consultations or analyzing consultation input; and

Answer requests for accommodations and arrange these accommodations.

Hiring and paying persons with disabilities as knowledge brokers will help to create more meaningful opportunities for persons with disabilities to participate in regulatory development processes, and to provide specific, relevant feedback about draft regulations to regulators. It will also ensure that government or regulator staff receive training prior to consultations such that they obtain more helpful, relevant input and create an environment that supports persons with disabilities in providing it.

#### 2. During Regulatory Consultations and Engagement Sessions

#### (i) Effective facilitation that ensures accessibility and inclusion

Facilitators and consultation questions should frame the dialogue during engagement processes in ways that promote participation and address power imbalances, systemic ableism and intersectional discrimination. These recommendations are based on the findings of the McGill study and observations of our project partners relating to the importance of concrete examples and clear and transparent communication during engagement processes. As well, the McGill study demonstrated that at some consultation meetings, the same people spoke over and over, and sometimes government staff dominated the meeting. This meant that many persons with disabilities just took in information and did not have a meaningful opportunity to contribute.

Based on these research findings, consultation questions should:

- Provide opportunities for persons with disabilities to relate their living experience to the proposed regulation;
- Refer to concrete examples that are relevant to the living experience of diverse communities of persons with disabilities;
- Communicate what has already been decided and where there is scope to influence regulator decision-making in a transparent way;
- Focus the input and conversation on topics relevant to the regulation; and

 Provide information about the proposed regulation and ask for feedback in plain language, in easy to understand and specific ways, rather than technical, vague, broad or redundant ways.

During engagement sessions and consultations, facilitators should:

- Ensure that the conversation proceeds in an orderly, accessible and inclusive
  manner (for example, by ensuring that people who need more time to construct
  their message are respectfully given this time without interruption, ensuring that
  participants have the communication supports or accommodations they need, or
  by asking people to give their name before speaking);
- Receive training on the use of plain language, and employ plain language whenever possible;
- Be knowledgeable about the subject matter of the consultation, the consultation questions and the scope of the consultation to keep the conversation on relevant topics; and
- Be mindful of power imbalances, systemic ableism and intersectional discrimination. Facilitators must ensure that everyone has the opportunity to participate and that everyone's participation is respected and valued. Facilitators should be able to skillfully create space for people to feel welcome to express their views.
- (ii) High level staff with decision-making power should attend in-person meetings and teleconferences

Persons with disabilities perceive their contributions as more meaningful when regulator staff attending a meeting have the power to influence decision-making. The presence of someone who has decision-making power could combat the perception by our project partners and participants in the McGill study that some regulatory consultations are proforma, with no real opportunity to effect change.

The regulator's representatives should promote a two-way dialogue, engaging with persons who provide input and sharing information about how this input will be taken into consideration when making decisions about the regulation. These staff members should be aware of power imbalances between them and the audience, and among different stakeholders, and ensure that they welcome and consider all perspectives.

#### (iii) Collection of anonymous disaggregated demographic data

During or immediately after a consultation, regulators should collect anonymous disaggregated demographic data about the persons with disabilities who participate. Care must be taken to ensure that demographic data is anonymized and securely stored. After the consultation is complete, regulators should examine who participated and whether there were communities who were missing or underrepresented in the consultation. By collecting and analyzing demographic data, regulators will be aware of which perspectives they receive and which are missing.

This recommendation is consistent with the findings of the McGill study and our legal research that some persons with disabilities are underrepresented in regulation development. For example, our research shows that person with disabilities who are racialized, Indigenous, newcomers, children and parents, gender diverse, LGBTQIA2S+, unaffiliated with organizations, and located in remote areas are often underrepresented in regulation development. Our research shows that these persons with disabilities may face additional barriers to participating in regulation development, and they have unique perspectives to contribute that regulators do not often receive.

Our project partners have also emphasized the importance of generational consultation, inclusive of persons with disabilities of all ages. Data should be gathered to determine if persons with disabilities of particular ages are underrepresented in consultations, so that they may be more effectively engaged in the future.

#### 3. After Regulatory Consultations and Engagement Sessions

#### (i) Transparency and accountability after consultations are complete

Regulators could improve transparency and accountability after consultations conclude by:

- Creating a standard practice to make submissions received publicly available (unless a participant asks that it be kept confidential): some regulators already do this, but others do not. Alternatively, regulators may publish minutes or summaries of consultation meetings, again with attention to confidentiality as needed.
- Sending follow-up correspondence to participants: everyone who participated could receive a relatively concise e-mail or letter in plain language, providing a

summary of the feedback that was received, documenting the disability groups that provided input and groups that were missing, and stating specifically what input will be used and not used, and the reasons why. This document should provide concrete examples of how feedback influenced the purpose, the structure and the wording of the regulation, or other elements of the government or regulator's work, such as the creation of guidance documents. It should be written in plain language and be made available in American Sign Language, langue des signes Québécoise, Indigenous sign language and in formats other than email for participants who don't have access to computers or the Internet.

 Consultation participants should be given least 3-4 weeks to respond, to allow them to clarify what they said and further explain anything that the regulator may have misunderstood. This further promotes two-way dialogue, consistent with our research findings described above.

Publicizing the feedback received during the consultation addresses our research findings which emphasize the importance of transparency in regulation making. Furthermore, the follow-up e-mail responds to the concerns raised by our project partners and McGill study participants, who expressed that they wanted regulators to acknowledge their participation and provide information about how their input was used. In particular, they did not find the lengthy "What We Heard" documents that some regulators release to be helpful. The follow-up e-mail could improve upon these reports by providing specific, concrete information about how the input from engagement processes will be used, consistent with academic literature regarding knowledge translation. This communication will help to provide more transparency and accountability within regulation development processes. It may help to address consultation fatigue by demonstrating to participants that their input is valuable, listened to and actively used by regulators to influence the outcome of a proposed regulation.

Recommendations for new processes that could happen alongside existing regulatory development processes:

#### Gatherings with underrepresented groups in an accessible, culturally appropriate way

As described above, our research demonstrates that some persons with disabilities are underrepresented in regulation development processes. Regulators could address this outside of existing regulation development processes by conducting additional meetings or gatherings with underrepresented persons with disabilities in a smaller, more informal settings to allow dialogue to take place.

#### These gatherings should:

- Focus on individuals and groups of persons with disabilities who have not participated in previous regulatory development processes and who may experience additional barriers to participation, such as those who have very restricted mobility, those who have speech or language disabilities and who may use alternative or augmentative communication and/or communication assistance, those living outside urban areas, newcomers with disabilities, racialized persons with disabilities, Indigenous persons with disabilities, youth with disabilities and other underrepresented groups. The collection and analysis of anonymous, disaggregated demographic data during regulatory engagement processes (recommended above) would assist regulators to determine which groups to target for these small group meetings;
- Employ a person with a disability from the relevant, underrepresented community, as a "knowledge broker" to co-design the gathering, facilitate or co-facilitate the meeting, co-design and deliver outreach to participants, and co-develop meaningful, accessible background information. It is particularly important that this person be from the community the regulator wants to engage, to ensure that the consultation is respectful, culturally sensitive, and conducted in a way that members of that community feel comfortable giving input. Small group meetings must be facilitated in a manner that attends to power imbalances, systemic ableism and intersectional discrimination to ensure that all participants have the opportunity to contribute and that all participants are respected and valued. (For more details see above recommendation regarding persons with disabilities hired as paid knowledge brokers);
- Recruit participants using a transparent selection process that engages diverse
  groups of persons with disabilities and Deaf persons by recruiting in multiple,
  accessible formats. Information should be published about the diversity of
  participants (in contrast, closed or secret consultations undermine trust in the
  regulation development process and make it more exclusive);
- Be conducted early in the regulatory development process before significant decisions are made;
- Be attended by government staff with the power to make decisions about the content of the regulation, which adds credibility to the consultation and demonstrates that input is received by people with decision-making authority;

- Be universally designed, prioritize individual accessibility needs by contacting participants proactively ahead of time about accommodations they may require, and be conducted in multiple formats;
- Compensate participants for their participation, and ensure that such
  compensation does not interfere with a participant's income support benefits or
  entitlement. Compensation should also be provided for accessible transportation
  to attend in-person meetings, costs of childcare, costs of attendants, costs of
  communication assistants, and other disability-related supports. This
  compensation is very important, since persons with disabilities often lack the
  financial and human resources to participate in regulatory consultations.
  Historical underrepresentation of certain groups may reflect this lack of
  resources;
- Provide participants with accessible, plain language background information that
  relates the living experiences of persons with disabilities to the regulation being
  developed. Background information should also include accessible, plain
  language information about the purpose of the small group meeting, what will be
  discussed, and guide participants as to the kind of input that would be relevant;
  and
- Should be publicly documented, so that members of the public can know which
  demographics were represented, what topics were discussed, and how the input
  received will be used by the regulator. This would contribute to transparency and
  accountability within the regulation development process.

# Funding and development of resources to support participation in regulatory development

This recommendation is based upon the legal research regarding the barriers to education that persons with disabilities experience, as well as the feedback from the participants in the McGill study and our project partners. This research and feedback demonstrated that there is a need for resources to build greater capacity within disability communities to participate in regulation development. Persons with disabilities who have not participated in regulation development before or who are not affiliated with larger organizations could particularly benefit from resources and supports in order to more meaningfully participate. For example, disability organizations could use this funding to educate members of disability communities about accessibility, their rights, and other foundational information that is important for participating in consultations.

Educational resources could include information about regulation development and guidance about preparing for and participating in consultations. It could include skills training, common technical topics that are relevant to accessibility regulations, the provision of legal information and advice about a particular regulation being developed, and other topics that persons with disabilities may identify. To ensure that these resources are relevant and useful, they should be co-developed, co-compiled, and co-updated with persons with disabilities. They must be made available in American Sign Language, langue des signes Québécoise, Indigenous sign language, in plain language, and other accessible formats that persons with disabilities request. They must relate the living experiences of diverse communities of persons with disabilities to the purpose of the *ACA* and the various areas in which regulations will be developed.

In addition to the development of these resources, funding should be made available for disability community initiatives that would support underrepresented persons with disabilities to participate in regulatory development.

#### Recommendations for changing existing regulatory development processes

#### Co-creation and collaboration

Our project partners and the participants in the McGill study emphasized their preference for co-creation and collaboration in accessibility regulation development, as opposed to consultation. This approach would reflect a more active and continuous role for persons with disabilities that encourages ongoing, mutual exchange of information with regulators. Persons with disabilities would be involved at multiple points throughout the regulation development process, rather than at two discrete "consultation" stages, as is the case currently. This would represent a departure from the current, top-down approach to include persons with disabilities in a more significant way. Furthermore, input from persons with disabilities could carry greater weight than it currently does. Regulators would need to do more to justify taking an approach that departs from the needs identified by disability communities. This would include providing transparent reasons regarding why input from disabilities communities on significant issues was disregarded. Regulators would need to explain why this higher threshold to reject input from persons with disabilities was met in this particular situation.

A regulation development process centered on co-creation and collaboration would be designed from the outset with persons with disabilities. It could use the findings and analysis from this project as a starting point for its work. It would implement principles of substantive equality, universal design and the section 6 principles in the *ACA*, described above. Such a process would likely be very different than existing regulation

development processes. It would offer opportunities to innovate, to develop collaborative partnerships between people with disabilities and regulators, and ultimately to create regulations that achieve the purpose of the *ACA* to create a more inclusive Canada.

Legislative reviews of the *ACA* and accessibility regulations by or in collaboration with persons with disabilities

Legislative reviews of the *Accessible Canada Act*, its regulations and accessibility standards are important to ensuring meaningful implementation of the *ACA* and accountability. Input from disability communities is crucial to determining whether and how these laws and regulations are achieving their intended purpose of reducing barriers. Our research and work with our project partners demonstrate that people with disabilities are interested in both the creation of regulations as well as their actual impact. A committee of persons with disabilities could provide a forum to evaluate this impact and ensure that accessibility regulations live up to their promise. The committee could also recommend regulatory or legislative changes. This committee should conduct its work taking to account the purpose of the *ACA*, including principles outlined in the *Charter*, human rights law, the *CRPD*.

For this committee to be effective, it would need to:

- Be sufficiently resourced to carry out its work (including legal support);
- Have an independent mandate;
- Undertake its work in a transparent way and be accountable to persons with disabilities; and
- Include persons with disabilities who are underrepresented in law-making and regulation development.

## Part VII: Opportunities for Future Research

The Meaningful Participation in Regulation Making Project may inform future studies regarding the participation of persons with disabilities in law making, regulation making, and policymaking.<sup>226</sup> The recommendations in this report provide practices that have the potential to improve the participation and inclusion of persons with disabilities in all of these processes. If any of these recommendations are implemented by regulators, further studies could address their effectiveness and additional steps that may be

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<sup>&</sup>lt;sup>226</sup> McGill study at 33

taken.<sup>227</sup> Any such studies that evaluate the effectiveness of the recommendations in this report must ensure that persons with disabilities have an active role in the evaluation.<sup>228</sup>

As well, ARCH's research identified the underrepresentation of many groups of persons with disabilities in existing regulation making processes. Due to time and budgetary constraints, the McGill research study only included 36 participants who did not represent all diverse disability groups or all regions of Canada.<sup>229</sup> Future studies could specifically focus on one more of these groups to analyze specific barriers they experience and corresponding solutions.

Finally, ARCH's research and recommendations focus on regulation making. However, both regulations and accessibility standards will play an important role in the implementation of the *ACA*. While processes to create accessibility standards are beyond the scope of this project, the principles of substantive equality and the *ACA*'s section 6 principles are equally relevant to the development of accessibility standards. Many of the recommendations made in this report are applicable to federal accessibility standard development, and can be adapted accordingly to that context. Future projects could apply ARCH's findings and recommendations to processes to develop federal accessibility standards.

### Part VIII: Conclusion

The *ACA* was enacted to enable the full and equal participation of persons with disabilities in society, in accordance with substantive equality, the *Charter*, and the *CRPD*. To ensure that accessibility regulations promote the highest level of accessibility, the Government of Canada, the Canadian Transportation Agency, and the Canadian Radio-television and Telecommunications Commission must involve persons with disabilities in regulation development in a way that reflects their living experience and supports them in providing helpful, relevant feedback.

To do so, these regulators must acknowledge the barriers that persons with disabilities experience in regulation making processes as they are conducted today. These processes can be bureaucratic and opaque, conveying that the feedback of persons with disabilities does not matter. They can alienate or exclude certain persons with disabilities, such as Indigenous persons with disabilities, newcomers with disabilities,

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<sup>&</sup>lt;sup>227</sup> McGill study at 33

<sup>&</sup>lt;sup>228</sup>Sherlaw & Hudebine, above at 11; Law Commission of Ontario, above at 108-109. See also: General Comment No 7, above at para 47

<sup>&</sup>lt;sup>229</sup> McGill study at 6-7, 32-33

children and families with disabilities, or persons with disabilities who live in remote areas. They are not always designed to be fully accessible.

Substantive equality and the section 6 principles of the *ACA* demonstrate that regulators should not simply rely on existing processes that are not accessible or inclusive. By implementing the recommendations in this Final Report, regulators can facilitate more meaningful, two-way communication and engagement that empowers persons with disabilities to give meaningful, relevant feedback during regulation making processes. This feedback and the participation of persons with disabilities is critical in ensuring that accessibility regulations address the needs of persons with disabilities and achieve real improvements in accessibility and inclusion for persons with disabilities across Canada.