Dialogue Summary

Enhancing Equitable Access to Assistive Technologies in Canada

8 June 2017





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McMaster Health Forum

Dialogue Summary: Enhancing Equitable Access to Assistive Technologies in Canada

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For concerned citizens and influential thinkers and doers, the McMaster Health Forum strives to be a leading hub for improving health outcomes through collective problem solving. Operating at regional/provincial levels and at national levels, the Forum harnesses information, convenes stakeholders, and prepares action-oriented leaders to meet pressing health issues creatively. The Forum acts as an agent of change by empowering stakeholders to set agendas, take well-considered actions, and communicate the rationale for actions effectively.

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Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the dialogue summary. The funders reviewed a draft dialogue summary but the authors had final decision-making authority about what appeared in the dialogue summary.

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SUMMARY OF THE DIALOGUE

Participants were receptive to the framing of the problem in the evidence brief, however, the deliberations about the problem led participants to identify a number of specific challenges in the province, including that: 1) root causes drive many of the challenges that individuals face in accessing assistive technologies; 2) complex patient journeys are not often accommodated in the current system; 3) financial challenges persist as a critical barrier to achieving equitable access to assistive technologies; and 4) difficulty in achieving innovation and ensuring that high-quality products come to market.

In deliberating about the elements of a potentially comprehensive approach for enhancing equitable access to assistive technologies, participants felt there was too much of a focus on incremental changes in the brief. Instead, participants collectively agreed that there was a need to balance incremental and aspirational changes. To do so, participants described a set of principles they felt should underpin both short- and long-term changes. In discussing element 1 (informing citizens, caregivers and healthcare providers to help them make decisions about which assistive technologies they need and how to access them), participants highlighted the need to adopt a common language, improve navigation services, and enhance access to individualized assessments. For element 2 (helping citizens get the most out of government funded programs) and 3 (supporting citizens to access needed assistive technologies that are not covered by government-funded programs), participants focused on the need to better align government programs with the needs of those requiring assistive technologies, as well as to coordinate public- and private-insurance coverage to minimize gaps. In addition, participants emphasized that over the long term there is a need to centralize and simplify the processes of approval, eligibility and assessment for assistive technologies, as well as implement a robust data collection and evaluation strategy.

Participants identified four priorities for moving forward: 1) spreading awareness of assistive technologies and engaging those using or in need of assistive technologies in crafting a long-term vision; 2) working with partners across health and social systems to determine what data should be collected on assistive technologies, and how to evaluate new technologies that enter the market; 3) building capacity among health professionals who are closely involved with the provision of assistive technologies; and 4) exploring the types of small-scale innovation projects designed to enhance equitable access to assistive technologies that could be funded and evaluated in select jurisdictions to determine what works.

SUMMARIES OF THE FOUR DELIBERATIONS

DELIBERATION ABOUT THE PROBLEM

Participants were enthusiastic about considering ways to enhance equitable access to assistive technologies in Canada. In deliberating about the problem, many echoed the challenges that were presented in the brief, including that:

- the many different definitions for assistive technologies can lead to confusion about what they are and what is covered;
- the need for assistive technologies is increasing;
- access to assistive technologies is inconsistent, which in some cases results in unmet needs; and
- system-level factors can make it complicated to access assistive technologies.

During the deliberations, participants identified four additional challenges, which build on those listed above: 1) root causes drive many of the challenges that individuals face in accessing assistive technologies; 2) complex patient journeys are not often accommodated in the current system; 3) financial challenges persist as a critical barrier to achieving equitable access to assistive technologies; and 4) there is difficulty in achieving innovation and ensuring that high-quality products come to market. We discuss each of these in detail below.

Root causes drive many of the challenges that individuals face in accessing needed assistive technologies

Participants identified four root causes that contribute to the challenges individuals face in accessing needed assistive technologies: 1) lack of a consistent definition for assistive technologies; 2) entrenched policies that have not been developed with unique client needs in mind; 3) theory not being used to drive the development of long-term policy goals; and 4) inconsistent or nonexistent data that can be used to identify the use and cost of assistive technologies.

First, throughout the deliberations participants returned to the challenges posed by a lack of a consistent definition for assistive technologies, the way in which it differs from other medical devices, and whether it should be thought of as a health technology, or whether it meets broader goals outside of the health system.

Box 1: Background to the stakeholder dialogue

The stakeholder dialogue was convened in order to support a full discussion of relevant considerations (including research evidence) about a high-priority issue in order to inform action. Key features of the dialogue were:

- 1) it addressed an issue currently being faced in Canada;
- it focused on different features of the problem, including (where possible) how it affects particular groups;
- it focused on three elements of a potentially comprehensive approach (among many) for addressing the policy issue;
- 4) it was informed by a pre-circulated evidence brief that mobilized both global and local research evidence about the problem, three elements for addressing the problem, key implementation considerations, as well as citizens' values and preferences which were identified from three citizen panels that preceded the dialogue;
- it was informed by a discussion about the full range of factors that can inform how to approach the problem and possible options for addressing it;
- it brought together many parties who would be involved in or affected by future decisions related to the issue;
- it ensured fair representation among policymakers, stakeholders and researchers;
- 8) it engaged a facilitator to assist with the deliberations;
- 9) it allowed for frank, off-the-record deliberations by following the Chatham House rule: "Participants are free to use the information received during the meeting, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed"; and
- 10) it did not aim for consensus.

We did not aim for consensus because coming to agreement about commitments to a particular way forward can preclude identifying broad areas of agreement and understanding the reasons for and implications of specific points of disagreement, as well as because even senior health-system leaders typically need to engage elected officials, boards of directors and others on detailed commitments.

Participants' views and experiences and the tacit knowledge they brought to the issues at hand were key inputs to the dialogue. The dialogue was designed to spark insights – insights that can only come about when all of those who will be involved in or affected by future decisions about the issue can work through it together. The dialogue was also designed to generate action by those who participate in the dialogue, and by those who review the dialogue summary and the video interviews with dialogue participants. Participants emphasized how the lack of a consistent definition underpins barriers to access by determining, in part, where funding for assistive technologies comes from, what organizations provide assistive technologies, who is eligible, and through what distribution channels.

Second, participants highlighted how current policies and programs for assistive technologies match a single disability (or individual need) to one or multiple technologies rather than taking a more holistic approach. For example, participants highlighted that for those individuals with more than one disability, each individual is outfitted with a different technology to meet each of their needs, but no consideration is given to how multiple disabilities or technologies may interact. Similarly, participants shared that individuals are often categorized according to the time period during which they were identified as having a disability and what caused the disability. As participants noted, this distinction makes sense in a siloed programmatic approach towards disability, when a distinction is being made between disability related to aging and those that result from conditions or life events. However, these differences do not hold up in reality and result in an approach that is not focused on the unique needs of individuals. In particular, participants highlighted how this type of siloed approach has caused duplicate services, two streams of access, and unequal provision of benefits to different parts of the population.

Third, participants stressed that there has been limited momentum towards developing long-term policy goals that are informed by theory and the best available evidence, as well as supporting action towards achieving any such goals. In particular, participants emphasized that policy has traditionally considered assistive technologies as being a responsive treatment following the onset of a disability rather than considering the role that it can play in health promotion and disease prevention.

Finally, participants highlighted the lack of publicly available data on the use and cost of assistive technologies in Canada. One participant emphasized that without this information, making the value case that is needed to attract policy attention would be challenging. Participants also noted that this lack of data likely stems from not having a "most responsible" or lead agency for assistive technologies in Canada. Instead, assistive technologies are provided by and paid for by a variety of different sources, including health services, social services, municipal and community-based organizations, charities and individuals' private funds. While each of these sources may have information on the quantity and costs of assistive technology, a full picture would require a concerted effort to map all the actors and begin to systematically collect data from each of them.

Complex patient journeys are not often accommodated in the current system

Participants highlighted three challenges related to how the system often fails to accommodate an individual's unique needs: 1) limited awareness of programs; 2) a lack of client-focused approach in assessing an individual's needs and pairing them with assistive devices that address them; and 3) individuals who face complex challenges are often neglected.

In relation to the first challenge, participants emphasized the lack of awareness of assistive technologies in the health system in terms of what is funded, among health professionals in terms of knowing what supports and technologies exist, and by the public in knowing where to go to gain access to needed assistive technologies. Participants noted that this limited awareness likely stems from the complicated landscape of assistive technology spend significant amounts of time and energy on trying to connect with people and/or programs that might be able to help them.

Second, participants discussed the limited focus that is spent on assessing an individual's needs and pairing them with one or more assistive technologies. Despite there being significant evidence to support the use of assessments in determining suitable technologies for an individual, participants expressed that in their experience these were not being routinely implemented. Specifically, participants noted that assessments for assistive technologies were often undertaken by health workers or assistants rather than by physical therapists

or occupational therapists, who participants saw as better trained to assess the client and determine the best supports for them.

Lastly, participants emphasized that important groups who face complex challenges are often neglected. In particular, participants spoke to the challenges that women with disabilities contend with and the need for a gendered analysis of the problems discussed in the brief. The participant who highlighted this issue focused on the idea that many of these women find themselves caught between their need for assistance and their role as caregivers. Another participant underscored the importance of considering those with intellectual disabilities as well as physical disabilities. Specifically, they mentioned how the narrative on "keeping individuals at home longer" and "maintaining independence" that is often used to promote assistive technologies was a disservice to individuals with intellectual disabilities who may be in need of assistive technologies, but require them in alternative settings.

Financial challenges persist as a critical barrier to achieving equitable access to assistive technologies

Participants identified four financial challenges related to access to assistive technologies: 1) financial burden placed on individuals; 2) limited coordination between public- and private-insurance coverage for assistive technologies; 3) sustainability concerns for health and social systems; and 4) difficulty knowing where to invest. For the first challenge, participants explained that individuals continue to face financial burden from having to pay out-of-pocket for their assistive technologies that they require to meet basic needs. While they described that there were some programs and financial supports available, it is often provided by a patchwork of government programs, private health insurance, community organizations and charities that differ substantially across communities, and that sometimes leave large gaps in coverage. Further, one participant described how the eligibility criteria between programs differs substantially and "are not focused on how to best meet the needs of an individual and assist them in remaining independent."

Second, participants spoke to the limited coordination that exists between what is covered publicly under government programs and what private health plans set as their scope of coverage. Some also explained how even for those with additional health insurance there is potential for gaps in coverage, which can pose financial burden on those in need of assistive technologies.

Third, participants linked a lack of action on enhancing equitable access to assistive technology to broader sustainability concerns for health and social systems. For example, some participants emphasized that a lack of action on using assistive technologies to support health promotion is a missed opportunity for enhancing the overall sustainability of health and social systems. Some participants also described the limited investment in assistive technologies as being a response to the sustained focus in health systems on acute-care needs. These participants explained that while assistive technologies are seen by many as preventive interventions, they are often not prioritized as such for investment or resource-allocation decisions. Other participants expressed frustration with this given that there are a number of low-cost upstream investments that could result in cost-savings in the future.

Lastly, without a substantial evidence base on the impact of assistive technologies, many participants highlighted how it will be challenging for policymakers to know where to invest. Similar to pharmaceuticals and medical technologies, one participant described that there is "always the latest thing, but we have no idea if it works." They further clarified that a systematic method of evaluating what to fund and what not to fund with regards to assistive technologies is needed in Canada.

Difficulty achieving innovation and ensuring that high-quality products come to market

Participants explained that they thought there was a lack of innovation in the assistive technologies market in Canada. By this, participants were clear that they did not mean that the market was not providing the most up-to-date technologies, but rather that there was a lack of focus on simple, universal-design and low-cost

solutions that can have a larger impact for more people than other more complex and expensive technologies. One participant described this as the result of "vendor push," noting "that the technologies we use come to us in a very reactive way" based on what industry has developed and determined, as opposed to being driven by those in need. The result may be a smaller number of high-quality products that are able to reach large populations coming to market. Moreover, participants highlighted that advances through innovation can be limited due to a lack of training and education among health professionals and among those using the technologies, which means that the full benefits of technologies are not optimized.

DELIBERATION ABOUT POLICY AND PROGRAMMATIC ELEMENTS OF A POTENIALLY COMPREHENSIVE APPROACH

In opening the deliberation about the elements of a potentially comprehensive approach described in the evidence brief, participants agreed that there was too much of a focus on incremental changes. Instead, participants collectively agreed that there was a need to balance incremental and aspirational goals that could bring about the larger changes they viewed as being needed to enhance equitable access to assistive technologies in Canada. One participant described the elements in the brief as "taking the current system as a given," and described how they felt that this was significant deviation from other jurisdictions that have made fundamental reforms, particularly around the adoption of the Convention of the Rights of Persons with Disabilities.

Participants emphasized that such a balanced approach will require short-term incremental changes that are guided by a framework and a set of principles that espouse the aspirational goals required for more fundamental changes over the long term. Participants identified the following principles to underpin this work:

- using a client-driven approach (i.e., engaging those affected by the issues in the change process);
- fostering agreement on a definition and/or bill of rights for those with disability;
- ensuring universal access for technologies that support instrumental activities of daily living (and thereby helping people lead independent lives without costly intervention from the health sector);
- ensuring a simplified approach accessing assistive technologies coupled with the flexibility needed to address an individual's unique needs;
- moving beyond a medical model to either a social or rights-based model (which was seen as helping to address many issues, including reducing prices and adopting a holistic needs assessment);
- fostering national leadership related to assistive technology, as well as partnerships with industry to achieve common goals; and
- fostering innovation not only for new technologies, but also for policy approaches that can be used to enhance equitable access (which could involve drawing on lessons learned from similar areas of policy, such as prescription drugs, but with the caveat that not all will be applicable and the potential risk of continuing in a medical model depending on the analogy used).

Participants also emphasized two specific long-terms goals that were not articulated in the evidence brief. The first is to create a centralized and simplified process of approval, eligibility assessment and provision of assistive technologies. The second was to implement a robust data collection and evaluation strategy that is based on common definitions to support both innovation (e.g., by being able to rapidly test new approaches) and accountability (e.g., to ensure investments are paying off).

Element 1 – Informing citizens, caregivers and healthcare providers to help them make decisions about which assistive technologies they need and how to access them

For element 1, participants emphasized the following two approaches that could be pursued to inform citizens, caregivers and healthcare providers to help them make decisions about which assistive technologies they need and how to access them: 1) enhance access to information and streamline the consumer experience; and 2) support approaches to individualized assessments to ensure the right set of assistive technologies are bundled based on what they need.

Enhance access to information and streamline the consumer experience

Participants generally agreed with the importance of the approach presented in the brief, expressing that there was lack of awareness about assistive technologies in the health system, and noting that this would be an easy place to begin to make changes in the short term. While participants did not provide concrete examples of how to increase awareness among each of these groups, they did identify two facilitators that they felt could increase the accessibility of the information that already exists. The first is to establish and begin using common definitions and a common language across organizations that are working with, or promoting the use of, assistive technologies. Many participants indicated that an important part of this that could be achieved in the short term would be to adopt the language that is used in the Convention of the Rights of Persons with Disabilities. The second facilitator identified was the need to break down the silos of disabilities and aging. In particular, participants emphasized the importance of ensuring that existing resources and information are relevant to both populations.

In considering how to improve the information that assistive technology consumers have and how to support their decision-making about what they need, participants highlighted the need to improve navigation services within the current system. Many felt that this would be important for addressing the challenges related to a complicated and hard-to-navigate system that were identified in the deliberation about the problem. Two complimentary solutions were also raised during the deliberations. The first was to simplify the process for gaining access to assistive technologies to enable individuals to navigate services and providers themselves, while the second proposed solution focused on creating a dedicated role for navigators, who could help individuals to access the right services and to be fitted with appropriate assistive technologies. Some participants noted that this role already exists in some jurisdictions, but that it is not equally available across the country.

Support approaches to individualized assessments to ensure the right set of technologies are bundled based on what they need

In deliberating about other ways to improve access to assistive technologies, participants highlighted the need for a client-driven approach, and supported the expansion and use of individualized assessments. Participants noted that this approach considers the individual as a whole, rather than fitting them for individual technologies based on each disability. Participants agreed with the idea presented in the evidence brief for bundling assistive technologies, but also emphasized the importance of using multi-purpose assistive technologies whenever possible. Prior to expanding either the use of individualized assessments or the bundling of technologies, participants suggested that health professionals would likely need some education and training on what technologies exist and how they should be fitted to individuals.

One participant raised the idea of whether digital solutions could be developed to enable this process. The participant described the potential of developing an algorithm that would, based on the entry of information from an individual, match them with the best combination of technologies to fit their needs. The participant highlighted that such a technology would both reduce the wait time for assessments as well as provide individuals some autonomy over the technologies they choose.

Element 2 - Helping citizens get the most out of government-funded programs

Participants agreed that more could be done to help citizens get the most out of government-funded programs, and focused their discussions both on what the role of the government should be in facilitating access to assistive technologies, as well as on suggesting changes that could be made to existing programs. Participants highlighted four approaches as being important for achieving this: 1) designing government programs with the aim of maximizing participation; 2) leveraging the efforts of existing organizations and actors across Canada; 3) integrating universal design into public policy; and 4) investing in and scaling up initiatives that have been shown to be successful.

Design government programs that aim to maximize participation

Participants voiced their frustration at the current government programs for assistive technologies, noting that eligibility criteria is often too narrow and does not consider the circumstances of those applying. In particular, participants highlighted the challenges of using tax credit-based programs to fund assistive technologies, when the majority of those applying will not be paying an income tax for the credit to be applied against.

Instead, participants expressed that the focus of government programs should be on ensuring individuals have access to technologies that are essential to support basic independence and instrumental activities of daily living. Participants described two ways that this could be operationalized. The first is to develop a list of essential technologies for which those in need could receive coverage. The second would be to develop a subsidy or entitlement to be spent on the assistive technologies that the individual chooses in partnership with a health professional. One participant described how this approach had already been implemented as part of a program from Veterans Affairs for housekeeping and home-care services. Other participants, while recognizing the autonomy that this approach provides to individuals, questioned the accountability and controls of implementing such an entitlement.

Leverage the efforts of existing organizations and actors across Canada

In considering government-funded programs, participants expressed the need for a clear value case to be made, particularly when advocating for additional government investment. To do so, participants highlighted the need to develop an evidence base that could support decision-making on what to fund. Some participants acknowledged the opportunity to add to the mandate of the Canadian Agency for Drugs and Technologies in Health (CADTH), an organization that supports decision-making about what drugs and medical technologies should be publicly covered. Those who supported this approach highlighted how this could build upon an existing expertise and legitimacy of the agency, as well as to raise the profile of assistive technologies in policy discussions. Further, participants believed it would contribute to creating a credible evidence base that could be used to make the case for funding. Other participants warned that having an organization such as CADTH champion assistive technologies could further medicalize the issue and marginalize communities that do not consider their disability to be health related, such as those with intellectual disabilities.

Participants also took inspiration from pharmaceutical advances in Canada and discussed the possibility of creating a pan-Canadian alliance for assistive technologies to mirror the pan-Canadian pharmaceutical alliance. Those who supported this approach believed that it would "provide a more formal channel for provinces to communicate and discuss how to review and fund assistive technologies." Further, participants described how this type of arrangement would support collective purchasing power better than that of individual organizations, which would in turn support more efficient procurement.

Integrate universal design into public policy

Participants expressed how there are opportunities to easily integrate universal design and considerations for those who may need assistive technologies when crafting public policy. One participant provided the example of requiring that municipal building codes include wider dimensions for closets to enable them to be transformed into an elevator should this someday be required by the residents. Participants emphasized how these changes would not involve a large upfront investment, but could result in significant improvements in the independence of individuals and in preventing future disabilities in the future.

Invest in and scale up initiatives that have been shown to be successful

One participant brought forward a number of examples of pilot programs for assistive technologies that had received public investments in the past that had been largely considered successful, but had ceased because the funding period had lapsed. The participant described how an important government investment moving forward would be to build on previous successes by ensuring sustained funding for programs that have improved awareness and access to assistive technologies. Participants agreed that while scaling up context-specific programs would likely be a challenge, investing in those with successful outcomes and strong community-based support would work towards filling some of the gaps in the current system.

Element 3 – Supporting citizens to access needed assistive technologies that are not covered by government-funded programs

Participants differed in the role they thought that the private sector should play in providing access to assistive technologies, with some envisioning a more prominent role than others. In either case, participants generally agreed that the private sector should be more complementary to the services that are publicly funded. To do so, participants emphasized the importance of two approaches: 1) coordinate public and private coverage; and 2) de-medicalize assistive technologies.

First, as mentioned in the problem section, participants discussed how there should be greater coordination between the public- and private-insurance coverage. Participants expressed that there was a role for the private sector to play in making technologies available, through cost-sharing models for those that fall out of the scope of public insurance.

Second, participants spoke to the need to de-medicalize some assistive technologies, explaining how "if they stop being so specialized, we can break down some of the barriers to their development and they may become significantly cheaper." A few participants in particular felt that the mark-up on assistive technologies comes from their classification as health devices and the need to undergo approval prior to being brought to market. However, it was discussed that this process should be re-examined to see where possible efficiencies could be found to reduce the barriers to entry and allow for more competition in the development of products.

Considering the full array of elements

In considering the full array of elements, there was a general agreement that a focus on both short-(incremental) and long-term (aspirational) change is needed. Participants noted that despite the many changes they wanted to make to how individuals access and use assistive technologies, they understood that these changes would take time, and that there was a need to make small improvements to the system in its current form. Participants highlighted incremental changes across all three elements that should be pursued. In element 1, this included adopting a common language, improving navigation services and enhancing access to individualized assessments. For element 2 and 3, participants focused on the need to better align government programs with the needs of those requiring assistive technologies, as well as to coordinate public- and privateinsurance coverage to minimize gaps.

Throughout the deliberations participants also emphasized that to move forward with any of the proposed solutions, there is a need for an organization or a close network of groups to 'own' the area of assistive technologies. There was however, some disagreement about whether this should be taken up by an existing organization or whether the development of a new agency that is able to straddle the medical-social divide may be a better fit.

DELIBERATION ABOUT IMPLEMENTATION CONSIDERATIONS

Discussion about the barriers to enhancing equitable access to assistive technologies generally focused on three themes: 1) lack of data for defining the value-add of assistive technologies; 2) difficulty in reaching consensus on new funding mechanisms to promote patient-centred care; and 3) increased demand placed on health providers.

The first major barrier noted by participants was a lack of data on the use and costs of assistive technologies. With a political agenda that is always in flux, participants noted that without a strong evidence base, it will be a challenge to create a narrative that is compelling enough to become a political priority and to spark change.

The second implementation barrier is a response to the call to move away from a segmented approach to care towards one that assesses and treats the entire person. One participant explained how shifting towards this approach will likely require a change in the incentives and remunerations of health professionals to encourage them to work together across functional areas. Participants generally agreed that these types of changes are often contentious and difficult to achieve a consensus on.

The third barrier to enhancing equitable access to assistive technologies was the increased demand being placed on health professionals. Participants discussed how large volumes of work and delivering increasingly complex care to patients may prevent physicians from having enough time to provide the patient-centred care and referrals required to support them in gaining access to assistive technologies.

Having discussed barriers, several participants highlighted three windows of opportunities: 1) a consultative federal government willing to work alongside the provinces; 2) the pending development of a National Seniors' Strategy; and 3) a Senate committee on assistive technologies that at the time of the dialogue was still accepting testimonials.

DELIBERATION ABOUT NEXT STEPS FOR DIFFERENT CONSTITUENCIES

During the deliberations about next steps, participants outlined what they would bring back to their constituencies and how their suggestions could work to advance solutions identified. Together the participants articulated four areas that they could begin to address:

- 1) spreading awareness of assistive technologies and engaging those individuals using or in need of assistive technologies in crafting a long-term vision;
- 2) working with partners across health and social systems to determine what data should be collected on assistive technologies, and how to evaluate new technologies that enter the market;
- 3) building capacity among health professionals who are closely involved with the provision of assistive technologies; and
- 4) exploring the types of small-scale innovation projects designed to enhance equitable access to assistive technologies that could be funded and evaluated in select jurisdictions to determine what works.





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