Accessible Communication

Developing recommendations and guidelines for augmentative and alternative communication to enable persons with motor and communication, and speech impairment to participate in employment

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"[AAC system] has changed my life. I was lonely and had given up on a good future, but now I feel loved by many loving people because I can talk with them. I had no way to express that I was bored and needed to learn with others"

To learn more about our project and to read our publications, please see our website:

www.queensu.ca/aac-caa

LAND ACKNOWLEDGEMENT

Acknowledgement
of Territory

Queen's University is situated on traditional Anishinaabe and Haudenosaunee Territory. To acknowledge this traditional territory is to recognize its longer history, one predating the establishment of the earliest European colonies. It is also to acknowledge this territory's significance for the Indigenous peoples who lived, and continue to live, upon it – people whose practices and spiritualities were tied to the land and continue to develop in relationship to the territory and its other inhabitants today. The Kingston Indigenous community continues to reflect the area's Anishinaabek and Haudenosaunee roots. There is also a significant Métis community and there are First Peoples from other Nations across Turtle Island present here today.

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Ne Queen's University e'tho nońwe nikanónhsote tsi nońwe ne Haudenosaunee tánon Anishinaabek tehatihsnónhsahere ne óhontsa.

Gimaakwe Gchi-gkinoomaagegamig atemagad Naadowe miinwaa Anishinaabe aking

INTRODUCTION

The United Nations Convention on the Rights of Persons with Disabilities [2], signed and ratified by Canada, recognizes communication as a human right. We all know that people with mobility disabilities have a right to physical access within the built environment, and, in the same way, people with communication disabilities must have communication access – "the means, supports, and opportunities to communicate effectively" [3].

This research seeks to provide guidelines towards the development of standards in the priority areas of "accessible communications" as well as "information and communication technologies". Benyon, Crerar, and Wilkinson [4] suggest three components to any computer system; interaction methods, interaction devices and interface design. Many interaction devices and methods exist to enhance physical access to a computer, ranging from accessibility options within the operating system through to a variety of input devices such as joysticks, touch screens and speech recognition software [5]. Research evidence indicates that technologies and augmentative and alternative communication (AAC) systems support interaction and communication in diverse settings and can enable participation in employment [6-8]. People with complex communication needs experience restrictions to social participation in areas such as education, employment, and the community [7, 9, 10].

The American Speech-Language-Hearing Association (ASHA) defines alternative and augmentative communication (AAC) technology as any technique or tool that helps individuals express thoughts, wants and needs, as well as feelings and ideas [11]. For the system to be categorized under "alternative", the technology must be used in place of the user's speech [11]. For the classification to be augmentative, the technology must be used to supplement existing speech by improving expression, transmission and message understanding, and enhancing communication itself [11, 12]. Examples of AAC include, but are not limited to, picture communication boards, line drawings, speech-generating devices (SGDs), tangible objects or eye-gaze technology.

AAC may help to overcome barriers as emerging evidence shows that AAC can positively impact communication and social participation [7, 13-16]. The ultimate aim of AAC services, which facilitate the access and use of AAC, is to support social participation [17]. Despite the acknowledged benefits and aims of AAC services, AAC systems are underutilized [18]. Research is needed to address barriers to AAC use. Previous research has identified service provision and service providers as important factors influencing the use of AAC [19, 20]. However, there are few standards guiding the development of AAC system integration.

While accessibility standards exist for software development (ISO 9241-171:2008) and interface design [21, 22], there is little guidance about how AAC hardware, including printed communication systems (e.g., lap tray or desk-mounted displays), electronic communication

boards, and speech-generating devices can contribute to effective social participation. This project seeks to address the paucity of information in this area, specifically in Canada, by iterative consultation with persons involved in the design, use, prescription, and funding of AAC.

The overall purpose of the project was to evaluate the current state of the art and provide guidelines towards standards in the development and access to AAC systems to enable communication of people with motor and communication and speech disabilities.

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PARTNERSHIPS

ISAAC Canada is a not-for-profit organization providing information to increase awareness and knowledge about people who use AAC. The first major purpose of the association is to educate and provide information to local, provincial, and federal governments within Canada regarding issues related to individuals who have little or no functional speech and/or writing. The National Council consists of the Executive Committee, at least one person who uses AAC systems, the past president, and one councilor from each region of the following, Region 1: BC, Yukon, Region 2: Alberta, Manitoba, Saskatchewan, Northwest Territories, Region 3: Ontario, Nunavut and Region 4: Quebec, Atlantic Provinces. ISAAC's members include researchers, therapists, educators, people using AAC, parents, and engineers. ISAAC aims to make people aware of the potential that AAC has to change the lives of individuals around the world who are unable to speak, and to find new approaches and technologies to help people communicate in different ways. In January (2020), ISAAC formed a partnership with the Assistive Technology Industry Association (ATIA), an association of manufacturers, sellers and providers of assistive technology (AT) products, equipment and systems that enhance learning.

Tracy Shepherd has been actively enrolled in this research. She is the Past-President of ISAAC Canada and the current president of ISAAC International. ISAAC and ISAAC Canada have offered advisory and consultative support, assisted with recruitment of participants, provided guidance with respect to research methods, conducted focus groups, and participated in the research. ISAAC Canada reached out to its membership with surveys, and provided consultation throughout with respect to development of consensus statements. ISAAC will also participate in dissemination of findings from the project (e.g., executive office distribution and the Canadian newsletter).

The Canadian Accessibility Network (CAN) brings together 20 organizations for research, collaboration, and knowledge exchange across sectors, disciplines, and industries, to minimize duplication of effort and maximize the building on others' strengths and achievements toward solutions. CAN is not a legal entity unto itself but instead a network of networks. Its operational hub is anchored at Carleton University in the READ (Research Education Accessibility and Design) Initiative. READ capitalized on opportunities through the CAN network to advertise to those with lived experience, including people with disabilities, to participate in research, and act as a knowledge mobilization (KMb) partner to help disseminate research findings both within CAN and Research Impact Canada (which is a partner in Future Skills Centre), provide guidance on the research project as a collaborator, and engage with the research committee of the CAN governance bodies.

https://carleton.ca/accessibility-institute/can/

TEAM MEMBERS

Dr. Claire Davies is an associate professor in Mechanical and Materials Engineering. Her lab is the Building and Designing Assistive Technology Lab where she seeks to increase the independence of persons with disabilities.

Dr. Batorowicz is an associate professor in the School of Rehabilitation Therapy. Her research focuses on augmentative and alternative communication services and enhancing social participation and inclusion of people with disabilities. She is a Chair of Research Committee of the International Society for Augmentative and Alternative Communication (ISAAC).

Dr. Shane Pinder is an adjunct associate professor in the School of Rehabilitation Therapy with interests in autism research. He began his career as an officer in the Canadian Forces, then civilian work in the defence industry, before transitioning to an academic career at the Auckland University of Technology and the Manukau Institute of Technology, where he led the School of Engineering.

Tracy Shepherd is a speech language pathologist who has a longstanding passion for Augmentative and Alternative Communication (AAC). Her research interests span many areas including reliability of SGDs, abandonment of technology, outcome measurement as well as other areas of clinical interest (teamwork, listening and family impact).

Glenda Watson Hyatt is an author, keynote speaker and a communication access advocate. Motivated by her personal experiences and the continual flow of social injustices faced by others living with communication disabilities, Glenda is a formidable voice for this systemically overlooked and devalued segment of our society.

Seamus Burnham's research is focused on augmentative and alternative communication (AAC) devices that require an eye tracking input method. He is investigating a link between the design of the AAC icons and the eye tracking performance of young children who are not yet literate. Seamus hopes that his findings improve this technology and increase the social inclusion of this population.

Jillian Henderson's research focus is to aid in the creation of the standards for the Accessible Canada Act, primarily working with individuals who use augmentative and alternative communication devices.

Stephanie Lackey is an occupational therapist who has worked in a range of settings, gaining experience serving diverse client populations including people impacted by neurodiversity, developmental disabilities, and serious mental illness. Recognizing the value of AAC in the lives of many people for whom she provided service, she aspired to become better equipped in her practice to support use of AAC systems.

Sonja Bonar's research interests include brain-computer interface systems pertaining to motor skills and movement assistive devices. She is currently researching motor imagery device design and motor imagery training implementation for people with cerebral palsy.

Diane McEachern's research interests are in augmentative and alternative communication and the implications for social inclusion of young adults, particularly around informal social networks, and their importance to successful employment opportunities. She has 20 years of clinical experience as a speech-language pathologist working with preschool and school-aged children, as well as adults with complex communication needs.

REVIEWING LITERATURE

Conceptual models and frameworks draw from theory, professional and personal experience, reflection, and insight [23]. These models can assist scholars and practitioners in understanding key variables, systems, and relationships among components [23]. The frameworks act as a tool for organizing ideas and classifying the relationships among different concepts [24]. A conceptual model of assessment may help guide AAC practitioners through the process of identifying a person's abilities, needs, and environmental supports and barriers [25]. This may translate to an appropriate match between the person using the technology, the technology itself, and contextual factors, which can increase the person's quality of life.

Scoping Review to understand assessment models for aided AAC

This scoping review identified three major areas of future research relevant to assessment models for aided AAC. First, there is a need to standardize the definitions of the descriptive traits used in the assessment of the personal abilities, environmental characteristics, potential assistive technology, and contextual factors. The definitions and components of these descriptive traits should be ascertained through discussions with a variety of AAC professionals, AAC recipients, and their support systems.

The second area of future research is the development of an assessment model or assessment models tailored specifically to individuals who may benefit from AAC. These models should be rooted in existing theories, research evidence, and the experiences of those in the AAC community. Finally, any future assessment models should include clearly defined, measurable outcomes related to assistive technology provision. This will allow for consistent outcome tracking across individuals or assessment teams and the comparison of the effectiveness of various models for research purposes. The suggested research is required to systematically develop and evaluate assessment models for assistive technology and aided AAC, which will lead to improving the efficiency of service delivery and most importantly the quality of life of individuals who can benefit from AAC.

Systematic Review to understand barriers and facilitators to implement workplace accommodations

Employment is an engaging experience in adulthood with personal and financial benefits that can contribute to quality of life [26-28]. The Organization for Economic Co-operation and Development found that the average employment rate of people with disabilities is 44%, much lower than the employment rate of 75% for people without disabilities [29]. Individuals who require AAC however, experience exceptionally low employment rates, estimated as low as 14% ([30] as cited in [9]). Individuals who use AAC may face additional challenges in employment due to a number of factors including having effective communication skills to ensure employment success, limited job-related networks, hiring processes dependent on interviews and barriers to access and use of AAC in the workplace [31, 32] (barriers listed in Tables 1 and 2). Previous case study reports have suggested that workplace accommodations such as assistive technology [33], on-the-job training [34], and modified tasks [35] can support adults who use AAC to participate in employment (facilitators in Tables 1 and 2). Appropriate accommodations may address barriers in employment, however there is lack of research regarding workplace accommodations and use of AAC and thus further research is greatly needed to inform accommodation processes.

Table 1. Personal Barriers and Facilitators
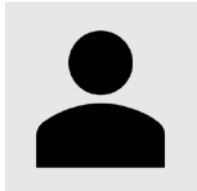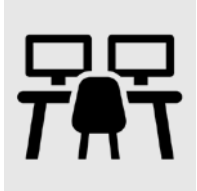
	Barriers		Facilitators
Personal Factors	Lack of adequate education	Education	Adequate education for the job
	Lack of previous experience	Work-related experience	Has previous volunteer slash work experience; Participation and networking opportunities
	Poor self-awareness; perception that employment is not possible	Character	Positive attitude; Motivated; Strong work ethic; Takes initiative; persistence
	Inability to acquire new job skills; Poor literacy skills	Skills & Knowledge	Self-advocacy; communicate needs to employer; Competency with technology; Educate colleagues on disability
	Reluctance to request help feelings of failure	Psychosocial	Acceptance of communication abilities and accommodations offered by employer

Table 2. Environmental Barriers and Facilitators

	Barriers		Facilitators
Environmental Factors	Technical issues with AAC and AT; AAC does not meet needs	Products and Technology	Access to and use of assistive technology and AAC; Features that support employment
	Noisy work environment	Built Environment	Safe physical environment; Working from home
	Interacting and building relationships with colleagues and social networks	Support and Relationships	Positive relationship with employer, supervisor and coworkers; Social and job-related networks
	Negative societal attitudes	Attitudes	Managers willingness to learn from employee and accommodate accordingly
	Inadequate transition services; Poor availability of information and services	Services Systems and Policies	Policies and practices that support accommodation; Funding for aids, transportation, job coaches, equipment
	Time required for alternative communication and fast-paced environment	Temporal Nature of Accessibility	Provision of time on the job to problem solve, develop accommodations, adjust to the workplace

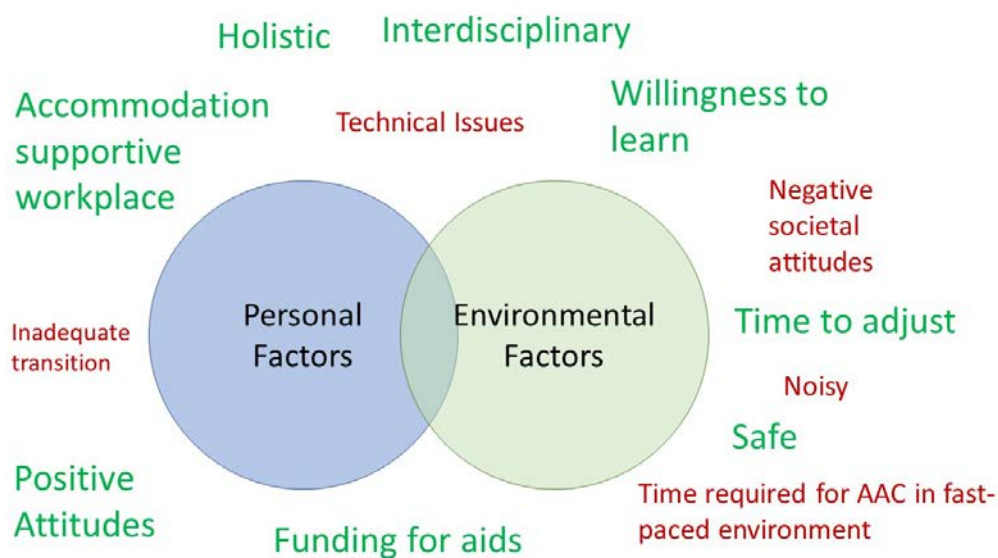## Discussion and Implications

Findings from this review revealed that barriers and facilitators to workplace accommodations exist both in and outside of the workplace. Barriers were predominantly environmental and most frequently related to attitudes and technology. Personal barriers included achieving job qualifications, level of education, work-related skills, and self-advocacy. Many of the factors influencing accommodation, such as self-advocacy skills, knowledge and attitudes of employers, workplace policies, education of employee, and perception of costs, were also reflected in a systematic review regarding workplace accommodations and physical disabilities [36]. Personal factors identified in this review would seem common to most people, however some environmental factors are unique to people who require AAC. For example, AAC technology was commonly identified as a facilitator while technological issues including unreliability and ineffectiveness were barriers. It is important for manufacturers, designers, and consultants to understand the technological issues faced by adults who require AAC to improve

accessibility and functionality of assistive technology. A combination of facilitators such as personal strengths, access to technology, and supportive relationships resulted in the effective implementation of accommodations. The findings suggest that it would be beneficial to increase support in the areas of career preparation, training, and transition to adulthood.

Addressing barriers and facilitators to implementing workplace accommodations is complex and it is important to consider interaction among personal and environmental factors when developing solutions. Addressing both environmental and personal factors requires a holistic, interdisciplinary approach, from career preparation to employment and through employment. More research is needed to address the implementation and effectiveness of workplace accommodations for people who require AAC.

Must ⬆ support in:
- career preparation,
- training, and
- transition to adulthood.

Barriers and Facilitators

Holistic   Interdisciplinary

Accommodation supportive workplace

Technical Issues

Willingness to learn

Negative societal attitudes

Inadequate transition

Personal Factors

Environmental Factors

Time to adjust

Noisy

Safe

Positive Attitudes

Funding for aids

Time required for AAC in fast-paced environment

GAINING ACCESS TO AAC DEVICES

Introduction

Studies have shown that the use of AAC technology can result in improved employment outcomes [37-39]; as well as promote independence, facilitate development of social relationships, and enhance educational opportunities [19, 40]. It has also been recognized that funding is an essential element in accessing assistive devices [40], and that AAC device selection is limited through provincially funded and charitable organizations and/or service provider programs [40]. However, caregivers and experts have expressed concern that some of these organizations and programs, such as the Government of Ontario's Assistive Device Program (ADP), are difficult to access and to apply for funding [41] introducing a barrier for individuals to obtain and use AAC technology. The Accessible Canada Act[42] requires the identification, removal, and prevention of barriers in federal jurisdictions by 2040. While Ontario's Assistive Device Program (ADP) has been reviewed [41], the other government funded and charitable organizations and/or service programs in each province and territory have yet to be evaluated for usability and accessibility.

Methods

We reviewed current organizations in Canada from which individuals can gain access to AAC technology. While each province contains at least one province specific program, currently this option does not exist for any of the three territories (Figure 1). We also identified what type of funding was available to persons who require it. Figure 2 shows that direct financial assistance is sometimes available, with some organizations also having loan programs. Other organizations only assist in filling out applications for funding. The website for each organization was assessed with respect to ease of finding information and applying for funding. Several evaluations of the website were conducted to identify what the organization provided including the lending or assessment of augmentative and alternative communication systems (as compared to more general assistive technology), readability of the website (Table 3), the cost to access services, eligibility criteria, and language availability. Table 4 shows the results of that evaluation.

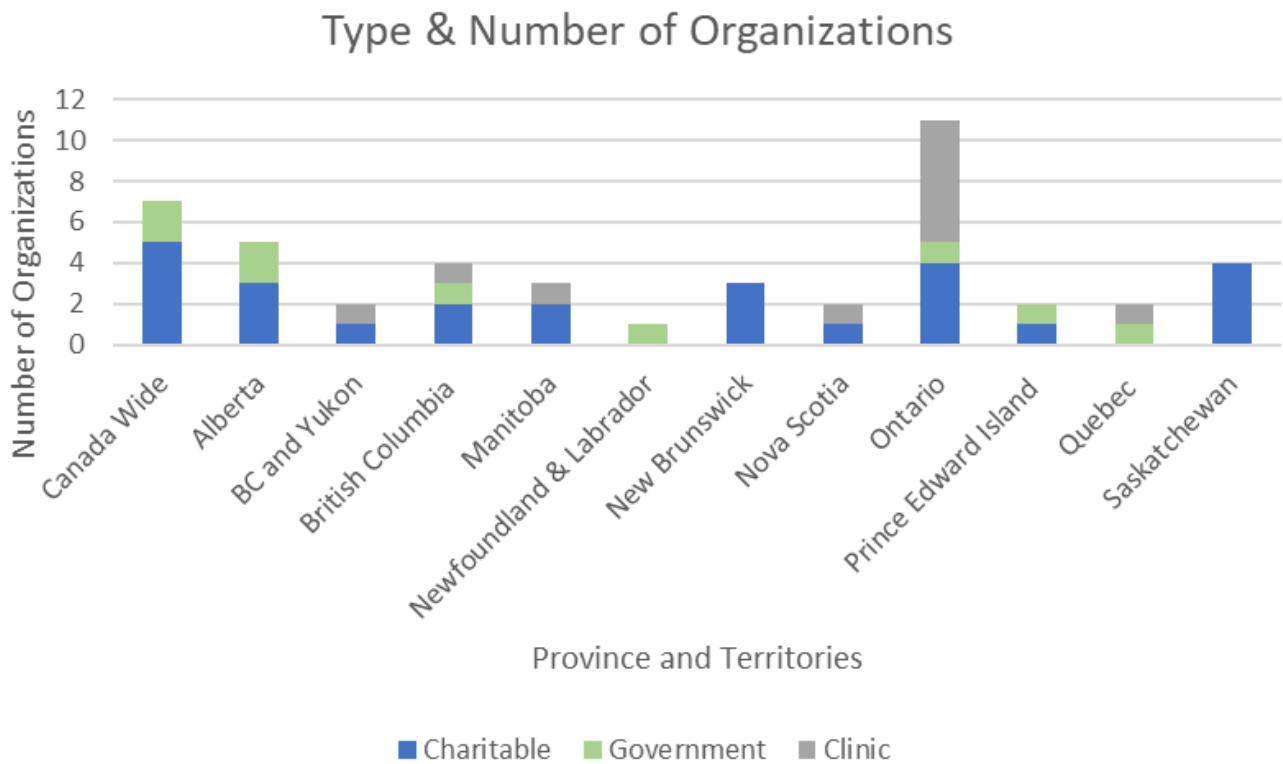## Type & Number of Organizations

Figure 1: Distribution of the number of organizations that exist to provide augmentative and alternative communication systems support to persons from the community.

Some of the organizations evaluated:

jordan'sprinciple
cheo-aacclinic aadl

oarc
easterseals accessability

adp
pmatcom   nihb   als
                  caya
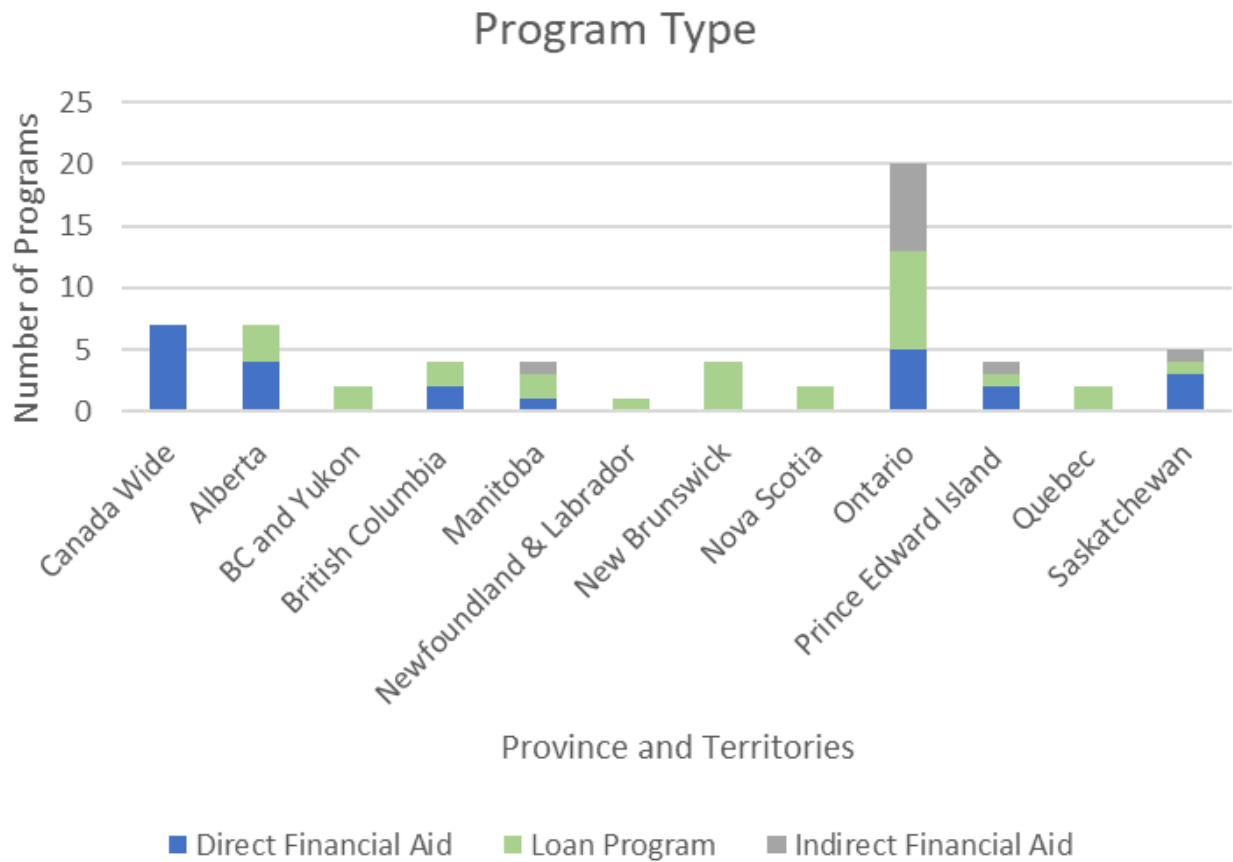
angels&friends saskabilities
dlc

Figure 2: Number of programs that provided access to funding for augmentative and alternative communication systems.

Table 3: Average reading level of websites through which AAC can be obtained.

	Flesch Kincaid Reading Ease	Flesch Kincaid Grade Level
Average	52	7
👍	79	3
👎	29	10

Table 4: Criteria for assessing websites to access AAC systems.

	Criteria	Yes	No	Unclear
About Program	Easy to find	33	12	0
	States a general procedure for application process	33	12	0
	States well detailed procedure for application process	8	37	0
	States general types of AAC Devices available	20	25	0
	States specific devices available to purchase/loan	4	39	2
	Device must be returned when no longer needed	24	2	19
Program Services	Clear they provide services for AAC technology	29	16	0
	Has minimum/base fee	11	12	22
	Offers free devices for trial	17	8	20
Program Requirements to Apply	Requires minimum income	5	22	18
	Requires company assessment	16	16	13
	Requires Professional Recommendation	30	8	7
	Professional recommendation must be company approved	4	25	16
	Requires pre-determined minimum skill set of devices	1	10	34
	Requires individual to sign up for program	16	5	24
	Individual must have already applied to different program(s)	15	6	24
	Device must be trialed	6	13	26
	Cannot already have/purchased device	14	6	25
Eligibility	Easy to find	25	20	0
	All Ages	13	18	14
	Youth Only	10	21	14
	Adult Only	8	23	14
	Disability Requirements/ Restrictions	34	7	4
Timeline	States general timeline on when/if you'll get device	11	34	0
	Considers "Urgency"	7	16	22
Language	Addresses the Individual using AAC technology	27	18	0
	Addresses the clinician/caregiver	24	21	0

Results

According to their websites, 70% of the organizations require a recommendation, assessment, or prescription from a health care professional to be eligible to apply for assistance, however these appointments can cost the individual up to $190 for an hour [43], a cost not covered by the programs [41]. These assessments also do not guarantee any assistance will be given and often several meetings are needed, with various people involved, before a recommendation or prescription can be made [41]. Alongside these costs, 11 programs have service fees or require the individual to cover 25% of any expenses incurred in purchasing devices. A lack of information about the timeline for assessment or to obtain devices in addition to lengthy waitlists can also provide a barrier in accessing the technology. For example, CAYA can have a wait list of up to 26 months, resulting in individuals "using dated technology by the time that it actually gets into their hands" [41]. There were also some ambiguities discovered within the eligibility criteria, such as the NIHB requiring the device not be used in "acquiring new communication skills", or PMATCOM where the applicant is "required to overcome a disability" to receive funding for assistive technology device. Additional barriers were imposed when obtaining and filling out the application forms as not many individuals can gain access to an Adobe Reader version 10 or higher, nor have computer storage or RAM large enough to download and process files as large as 2MB.

Conclusion

There are significant barriers that can prevent an individual from gaining access to AAC technology in Canada even though supports are provided. AAC device selection and provision is limited through government funded and charitable organizations and/or designated service provider programs [40] and it is important that the process to access these programs is made to be clear and barrier free.

For AAC system access to be barrier free, the process for applying to available programs must be clear and barrier free.

EQUITY IN COMMUNICATION: GOVERNMENT WORKPLACES

Introduction

Both the Employment Equity Act (EEA) [44] and the recently enacted Accessible Canada Act (ACA) [42] aim to identify and remove barriers in employment. To comply with the ACA, employers will need to adapt in recruiting, retaining, and promoting Canadians with disabilities by January 1st, 2040.

Methods

In response to recent social injustice events, the Privy Council Office of Canada issued a "Call to Action on Anti-Racism, Equity, and Inclusion in the Federal Public Service" on January 22nd, 2021. These letters were evaluated to better understand the implementation of strategies within the public sector to increase inclusion in employment.

https://www.canada.ca/en/privy-council/corporate/clerk/call-to-action-anti-racism-equity-inclusion-federal-public-service.html (accessed May 28, 2023)

Results

Ninety deputy heads responded by letter detailing the action their organizations have taken to date [45]. Using the "distribution of public service of Canada employees by designated group according to department or agency" table [46], it was calculated (Table 5) that the overall representation of employees with disabilities (5.6%) is below their workforce availability (WFA) and was calculated to be 9.0% (Treasury Board of Canada Secretariat, 2022, Persons with disabilities section, para. 2). The entities within the Canadian Public Service that employed people with disabilities of 5.6% or greater totaled thirty-three. From this total, 29 met the call and provided letters of implementation to the Call to Action. Four did not provide letters.

As a result, only 29 organizations responded who employed people with disabilities at a number/percent equal to the national average (which is also lower than representation by population). It is important to view these letters as a snapshot in time rather than as detailed reports of accessibility and inclusion initiatives undertaken. However, private and many public sector employers have been *legally obligated* to accommodate employees with disabilities up to the point of "undue hardship" for the past 26 years.

Initial analysis of these 29 letters shows that actions relevant to employees with disabilities include establishing Accessibility champions, Advisory Committees, and employees with disabilities networks; creating Accessibility Action Plans; reviewing policies, programs and initiatives using Gender-based Analysis Plus to identify systemic racism, and barriers to accessibility and disability inclusion; piloting the Government of Canada's Workplace Accessibility Passport; committing to include universal accessible washrooms in their workplace retrofits; and offering a medical exemption to the Official Languages Training Program for employees for whom learning an additional language would be problematic.

Based on the actions outlined in the letters, there was confusion in the distinction between Accessible Canada Act [42] section 5.c "information and communication technologies" and 5.c(1) "communication, other than information and communication technologies". As an example, accessible websites are listed as actions taken under

Table 5: Prevalence of disabilities in adults in Canada, 2006 [1].	
Type of disability	Adults aged 15 years or older (%)
Pain	11.7
Mobility	11.5
Agility	11.1
Hearing	5.0
Seeing	3.2
Learning	2.5
Psychological	2.3
Memory	2.0
Speech	1.9
Developmental	0.5
Other	0.5

5.c(1) rather than 5.c. According to the visual representation of the ACA [47], "Communications," presumably referring to section 5.c(1), means "Barrier-free services and spaces for persons with communication disabilities". This suggests clarification is needed in the publicly available information as well as in instructions provided to organizations required to file accessibility reports in accordance with the ACA.

The inclusion of employees with disabilities in these letters varied greatly. Some organizations did not mention any actions or initiatives related to this equity-seeking group nor to accessibility. A few initiatives were disappointing given the Employment Equity Act has been in effect since 1995 [44]; for example, committing to include universally accessible washrooms in their workplace retrofits; and providing guidance to staff on creating accessible documents. A far larger number of actions were encouraging and included establishing accessibility champions, advisory committees, and employees with disabilities networks; creating accessibility action plans; reviewing policies, programs and initiatives using Gender-based Analysis Plus to identify systemic racism, and barriers to accessibility and disability inclusion; smaller organizations leveraging external resources; piloting the Government of Canada's Workplace Accessibility Passport. Offering a medical exemption to the Official Languages Training Program for employees for whom learning an additional language would be problematic will benefit employees with communication disabilities, particularly those who use augmentative and alternative communication (AAC).

Significance

Nearly half a million Canadian adults are living with speech disabilities. Developing a strategy to promote equity in employing these individuals would tap into an underutilized labour pool. Increasing the employment rate of this segment of the disabled community could result in thousands of Canadians with communication disabilities being employed, increasing financial independence, meaningfully contributing to society, and, hence, improving their overall quality of life.

1.9% of the Canadian Population has a Speech Disability!

PARTICIPANT ENGAGEMENT

A Delphi study, informed by the CREDES (Conducting and Reporting Delphi Studies) is a method to achieve consensus through anonymous controlled, iterative feedback [48]. The opinions of experts are sought in a non-confrontational manner and provided back to the panelists for additional feedback. The first two phases of a Delphi study were conducted to elicit expert responses from people across Canada and to achieve consensus leading to recommendations for AAC for persons with speech, communication and motor control impairments who seek employment within Canada. The first phase of the study included focus group interactions (see distribution of participants in Figure 3) while the second included a survey. Such a method is recommended to access a geographically dispersed group of experts. The experts in this case included persons who use AAC technology as a primary means of communication, caregivers who assist with AAC integration, AAC practitioners (e.g., occupational therapists, speech-language pathologists, educators), and technicians and manufacturers who consult on AAC system design. Any person who interacts with AAC technology in some form was invited to participate.
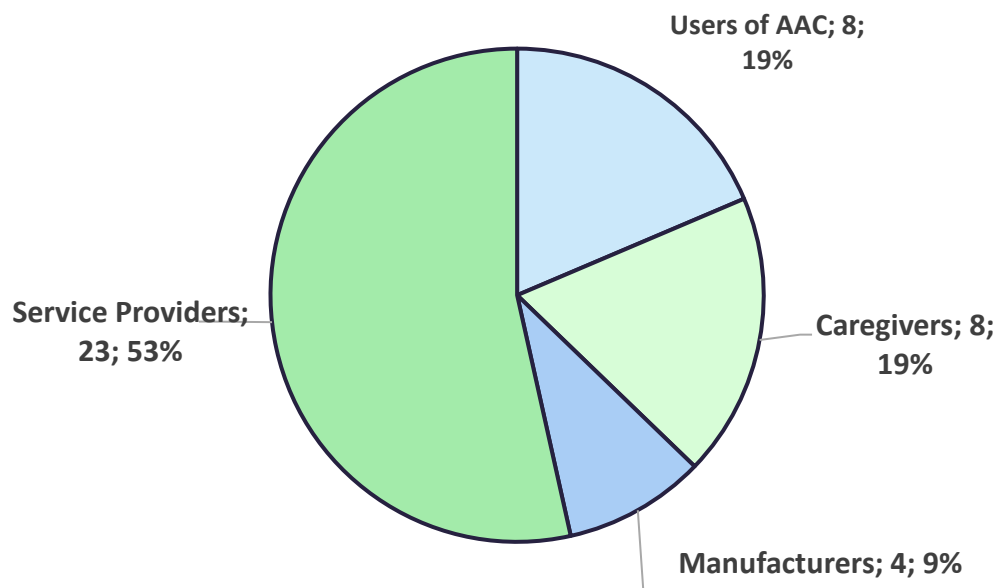

Figure 3: Total number of participants involved in focus groups and interviews.

FOCUS GROUPS

Connection and collaboration with members of the community is essential to ensure effective development of recommendations. Co-design is "an umbrella term covering both 'community design' and 'participatory design'. As such, [co-design is defined as] the effort to combine the views, input and skills of people with many different perspectives to address a specific problem". We used this approach in the development of recommendations to ensure collaboration from clients and families, and those working within Canada in the design and practice of AAC. Persons with disabilities, AAC expert clinicians, persons from the Canadian Chapter of the International Society for Augmentative and Alternative Communication (ISAAC), and the Canadian Accessibility Network (CAN) were involved as expert advisors and took an active role in making decisions that guide the project.

Working with end user experts (users of AAC technology, occupational therapists, caregivers), we elicited information about the design and effective use of AAC systems in Canada. Although technologies exist for modified or alternative access, many are abandoned after a few weeks[18]. We sought to determine "what has worked?" and "how?". We recruited participants with different physical access issues to provide input. Eight focus group discussions were undertaken to assist in identifying effective hardware components and strategies for use. One of these focus groups was undertaken in French but was translated to English for the purpose of analysis[1]. Recruitment of focus group participants was aided by our two partner organizations, the International Society for Augmentative and Alternative Communication (ISAAC) and the Canadian Accessibility Network (CAN). ISAAC's members include researchers, therapists, educators, people using AAC technology, parents, and engineers.

Purposive sampling was used to identify, screen, and subsequently select participants. The participant focus attempted to highlight the diversity of families and experiences to help us better understand the requirements for a variety of population groups.

The participants were asked to consider open-ended task scenarios based on the earlier identified requirements identified through the scoping and systematic reviews. The key areas of importance with respect to the requirements in the design and effective use of technology for AAC were identified using the guiding questions identified in Table 6.

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[1] Quotes provided from focus groups are presented in English (or French translations of English quotes) to maintain confidentiality of French participants given only three participants.

Confidentiality and Consent

All participants were provided a letter of information and consent prior to participation. Participation occurred using Zoom and the data were recorded after consent was verbally established. Participants were encouraged to create a pseudo name to be used in the interview to protect identity. This name was used during the interview and was part of the transcription and video/audio recording.

Table 6: Focus group questions

BEFORE FOCUS GROUP:
How would you describe your roles and relationship with AAC Systems? With what systems do you have experience?

	Person who interacts with AAC	Person who assesses and provides suggestions for a client who seeks to use an AAC system	Person who designs, manufactures, or sells AAC systems (including software)
Motivation	*Why do you want to use AAC systems? What type of AAC systems do you use or wish to use? Why did you choose those specific systems?*	*Why do you recommend AAC systems?*	*Why do you provide AAC technology systems? What motivates you to make/sell AAC products?*
Barriers	*What are the barriers to using AAC systems?*	*What are the barriers to recommending AAC systems?*	*What are the barriers to making / selling AAC products?*
Enablers	*How are you enabled or how do you enable yourself to overcome the barriers? What ways do you wish you could be enabled?*	*What methods enable you to effectively assess different AAC options with a specific client (feature matching, GAS)?*	*What enables you to design, manufacture, or implement effective AAC Systems?*
Outcomes	*How do you measure the success of your AAC system?*	*How do you measure success of your service to meeting client needs?*	*How do you measure success of an AAC system?*

Participants

Service Providers: Canadian service providers can provide insight on current practices in AAC services including strengths and challenges. This study aimed to explore the perspectives of service providers on the provision and use of AAC systems and services and identify key factors to the access to and use of AAC systems. Service providers included in this study work in Canada, with individuals who use AAC systems regardless of their professional background, and have a role in the recommendation and provision of AAC systems and/or supporting individuals with daily use of AAC.
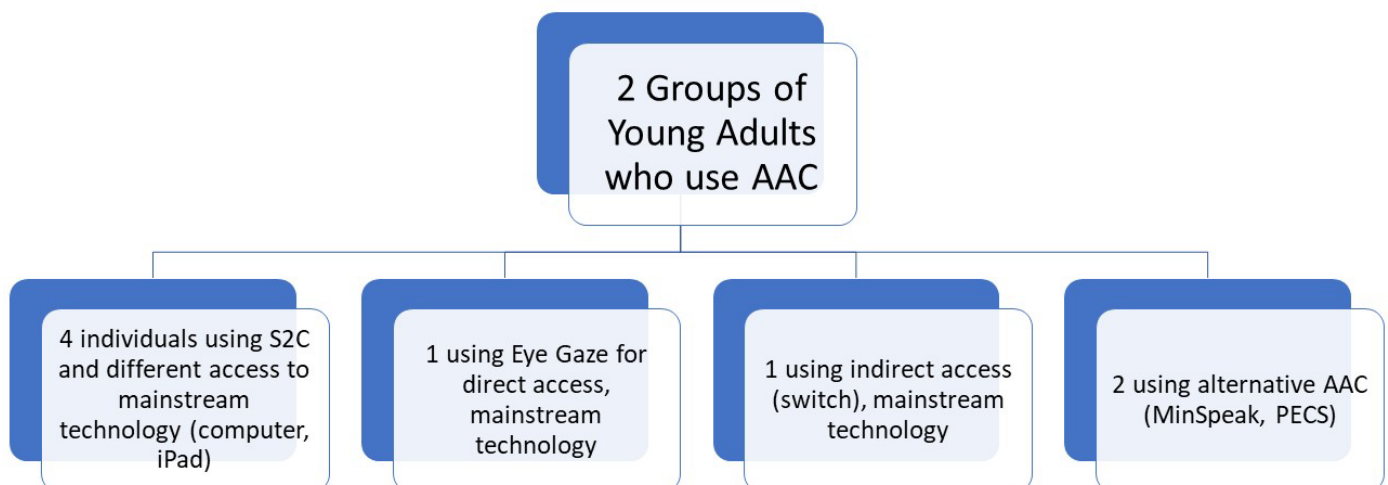
Young Adults and their Caregivers: We sought to explore the experiences of young adults and their caregivers about the key areas of importance as to design and use of the AAC systems. Six of the eight young adults used mainstream technology. Four used a combination of spelling to communicate and standard typing (iPad, computer). One person used eye-tracking and another used switches. Two individuals used speech generating devices.

Manufacturers and Technicians: AAC manufacturers and technicians act as key stakeholders in the AAC community as they develop AAC systems and provide support and training to individuals who use AAC. Canada has a limited scope for rehabilitation engineers, technicians and manufacturers within the area of AAC technology. There are thought to be approximately 20 technicians at AAC clinics within Ontario (the province with the greatest population) and two AAC technicians employed through the AAC centralized equipment pool. Some Canadian provinces only have one assistive technologist available for the province. This focus group included one manufacturer of an AAC application and three AAC device technicians from multiple provinces within Canada.
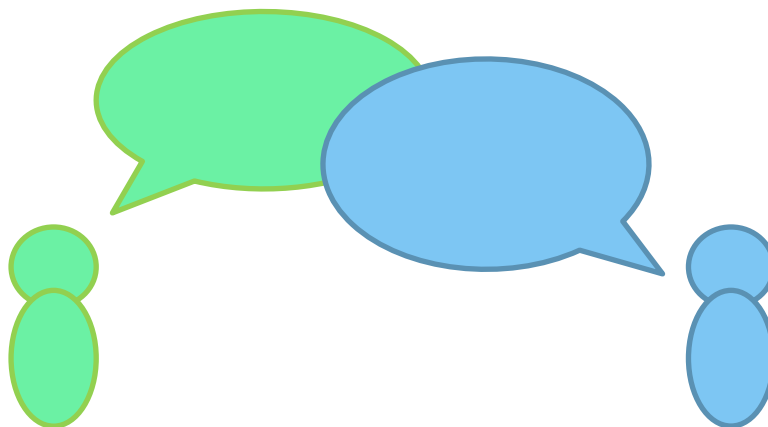
THE LANDSCAPE OF AAC SYSTEMS IN CANADA

The data from the focus groups were transcribed verbatim. Data were analyzed using Braun and Clarke's [49] reflexive thematic analysis. Recognizing the importance of researcher subjectivity within reflexive thematic analysis, each author created a reflexivity statement prior to data collection which described their relationship with the topic based personal and professional background, experience, and perspective [50]. Team meetings occurred regularly during data collection and data analysis. Different perspectives among the team members contributed to rich discussions and the trustworthiness of the findings. At least two people coded each transcript, and the group together analyzed the data following the process of reflexive thematic analysis as described by Braun and Clarke [49, 50] to generate themes. The researchers followed the main phases of reflexive thematic analysis: familiarization with the data, systematic coding of the transcripts, generation of themes from codes, theme development, and defining final themes [49]. Participants identified the fact that effective design for aided communication is complex and individualized. It aligns the components of personal and environmental factors, the design and maintenance of technology, access to professional skills and support, with system-wide funding access. Data analysis resulted in eleven main themes that represent the perspectives of Canadians with respect to access to and use of AAC systems: Goals, Societal Attitudes, Personal Factors, Informal and Formal Supports, Factors that relate to AAC systems, Aspects that influence interaction with technology, Service Delivery, AAC systems and Services, Environment (physical, school, social), Financial Aspects, and Human Rights Issues. These are further discussed.

```
                    ┌─────────────────┐
                    │   2 Groups of   │
                    │  Young Adults   │
                    │  who use AAC    │
                    └─────────────────┘
```

| 4 individuals using S2C and different access to mainstream technology (computer, iPad) | 1 using Eye Gaze for direct access, mainstream technology | 1 using indirect access (switch), mainstream technology | 2 using alternative AAC (MinSpeak, PECS) |

Themes Identified

Central circle: **AAC**

Surrounding themes:
- Goals
- Societal Attitudes
- Environment
- Personal Factors
- Informal and Formal Supports
- AAC Systems and Services
- Service Delivery
- Factors Related to AAC Systems
- Interaction with Technology
- Financial Resources
- Human Rights Issues

target

Goals

Participants using aided communication emphasized that the ability to pursue life goals of their own choosing truly felt like thriving. They wanted to be able to form strong relationships with friends and partners. Increased ability to communicate effectively also provides for autonomy and the ability to act on one's own values or interests. Young adults shared their life aspirations and pursuits - some were students, some were pursuing careers as writers, others had taken on strong advocacy roles, locally and nationally. Participants believed that a person who uses aided communication should be able to achieve meaningful communication beyond that of meeting basic needs like food requests. One of the most important factors is that of safety. One participant shared their experience about the importance of being able to speak out about sexual abuse as part of a nonspeaking population. They stated, "the sad truth is that many nonspeaking people are sexually abused. Being able to tell the police and seek help to heal has been huge for me." The ability to express emotion allows the individual to gain empathy as well as share in exciting experiences. All participants identified the great importance of social belonging with access to AAC technology.

> "we give goals for every trial that we do, and those are followed up on and reported by family and school."

Service providers recognized that goals are an important guiding factor in assessment and recommendation. As stated by a speech language pathologist (SLP) participant, "when we are assessing a client, we give goals for every trial that we do and those are followed up on and reported by family and school." Another participant, an occupational therapist (OT), explained that the goals of the individual who uses AAC influence recommendation with consideration for functional goals as well as "device access goals...and in what environment [is a client] wishing to participate in these goals." Additionally, achievement of individualized goals was considered by many service providers as a measure of success of AAC services.

Societal Attitudes

society

attitude

Participants revealed that societal attitudes and misconceptions around those who talk (and/or look) differently remain some of the most entrenched barriers to successful aided communication use. The generalized use of mainstream technology has failed to progress into understanding or acceptance of alternative AAC devices. The young adults discussed how the public did not regard alternate access methods for computers, such as head switches or eye gaze tracking as acceptable methods of communication. Caregivers confirmed an increasing pressure to move to mainstream technology choices from specialized, alternative AAC systems, if possible, to reduce the stigma of being different. One caregiver noted the following about their care receiver "When he used a letter board, there was always a stigma with it. He moved to an iPad, and it was suddenly, all the stigma, all that mystery was gone. People could just believe in him right away, and that's not fair. Another commented "We have to adapt to something that doesn't intimidate other people because they look at her MinSpeak and they're just like oh, I don't understand".

> "When he used a letter board, there was always a stigma with it. He moved to an iPad, and it was suddenly, all the stigma, all that mystery was gone. People could just believe in him right away, and that's not fair."

Aided communication users remarked they would make choices to use mainstream technology to increase opportunities for social inclusion, even if those methods were more effortful for them, and less efficient than their specialized AAC device. Another caregiver noted about their care receiver: "Her device is great because she can actually be more included in society. Communication leads to belonging".

Looking and sounding different led those who communicate with AAC systems to feel marginalized. The participants discussed how others often regarded them as stupid or as having nothing to say. At times, a distrustful, under-informed society challenged pre-programmed messages and an electronic voice as "not their own." Persons who use AAC systems were held to different standards, having to be perfect or better than everyone else to be respected. Those who use AAC, and their caregivers, recognize a further goal – the desire to contribute to society. This is bigger than personal occupation or social belonging. They advocate for a future where those who use AAC to communicate are valued without having to prove themselves,

Persons who use aided communication stressed that they feel like a burden to others leaving them emotionally exhausted. We found that participants of the focus groups stressed the desire for society in general to "have more patience", to slow down, accept other forms of communication, and allow individuals communicating with AAC to participate in conversations, reflecting that their input is valued. As one participant, an OT, shared, "I often find some of my clients run into is not being given enough time to get their message written down. They're composing it and the communication partner might not realize they need to give them a little extra time." Another service provider participant, felt that attitudes about AAC have change positively with increased exposure to AAC, explaining that, "Now that we travel [outside city centres], there's way more devices being used in [smaller] communities and people are recognizing that it's helpful. And actually, I'm quite impressed with the amount of change that's happened in such a short time, in terms of people's perception of using AAC for communication."

"I often find some of my clients run into is not being given enough time to get their message written down. They're composing it and the communication partner might not realize they need to give them a little extra time."
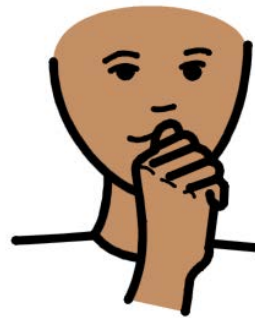
Personal Factors

Personal factors that affect the effective use of AAC communication include sensory processing, fatigue, general health, and literacy. Persons who use AAC systems may have difficulties with sensory regulation and the ability to regulate affects their use of the AAC system. Fatigue in interaction can also affect effective communication, as many systems require both physical and mental effort, both of which diminish with increased use in a given time period. If an individual is sick, this negatively affects their ability to communicate and express their emotions, hindering interactions with friends and family. Finally, literacy is an important contributor to interaction, both from the perspective of educational literacy, but also the ability to interact with mainstream technology, as that can enable increased engagement.

personal

influencing factor

Tied in with goals, the focus on what is most important to the user as well as their caregivers, will affect their acceptance of the AAC system. Factors that may affect the individual's acceptance of the AAC systems are: 1) The language(s) being used, 2) The ability of the system to help achieve goals, both in the short term and the long term, 3) The manner in which the system is accessed, 4) The age of the individual as well as their current life-stage, 5) Their cognitive abilities, 6) Their vision and hearing abilities and 7) Their level of independence. Each client of an AAC system will have personal circumstances that affect the prevalence of each of the sub-factors in how they respond to the AAC system. This reinforces the importance of tailored assessment models.

Preferences of the individual were also discussed by service providers as a factor in decision-making around AAC recommendations. As stated by an SLP, "sometimes the child decides...I will give out a trial device that has more than one app on it and the child has decided that they prefer one over another." Another SLP explained "I know that for some of the children...how it appears is an important feature to them." The literacy skills and vocabulary of the client was also taken into account and one participant explained that they "trial a number of different devices and vocabularies" to help determine what meets the individualized needs of the client.
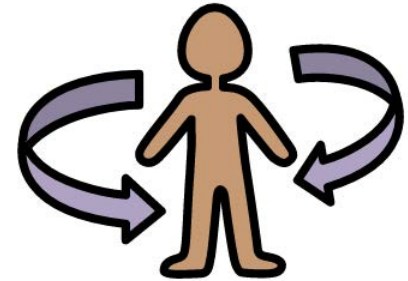
support

Informal and Formal Supports

Knowledge is a key factor to AAC access and use, and disseminating knowledge to service providers and other stakeholders is critical. AAC providers may benefit from ongoing education, training, and people within their network to support their knowledge. Service providers could benefit from employer support, such as time and opportunities, to engage in professional development. Additionally, AAC service providers are well-positioned to share their expertise to other stakeholders to increase understanding of AAC more widely.

Our participants noted that the consistent support of a primary caregiver was essential for successful aided communication. Being able to extend this support to a collaborative, professional network optimized an individual's proficiency with communication. This required mutual respect and an environment of creative and open-minded teamwork. Balancing skill sets of family members and professionals takes time and effort but is essential to identifying the optimal AAC system, and for promoting and maintaining its effective use over time.

We found that having a larger, informal community of support that promoted social interactions with peers was considered crucial for motivation and continued use of AAC systems over time. The participants mentioned how aided communication was much more effortful than using natural speech and they discussed a lack of training and support for skilled communication partners. The absence of knowledgeable communication partners was noted in all settings, including hospitals and other healthcare settings, schools, and adult vocational day programs. Participants noted a systemic inadequacy in understanding the amount of training and ongoing support necessary for individuals who use AAC. Participants noted that autonomy, achieved with the support of community and caregivers, was a key measure of success for individuals using communication aids.

Furthermore, the highest social achievement, belonging and inclusion, was attained when people using AAC successfully developed an informal support network, allowing them to feel heard and valued by peers. They distinguished peer relations as critical and uniquely different than support personnel or family relations.

For participant caregivers, being able to hear the "true voice" of an individual was a critical measure of success when assessing the effective use and design of an AAC system:

"When there's a level of confidence that you're hearing the individual's true voice, that's my highest measure of success."

They noted that they would discard systems that were limited in vocabulary and scope for topics such as emotions and feelings. They reflected on trying to "keep up" by adding vocabulary symbols and topics as a child developed and interests arose. Often, the potential of "limitless possibilities" was the driving force to keep them searching for a better communication system.

The caregivers in our focus groups all emphasized the importance of a communication system that allowed for personal security and safety. To promote the autonomy of an aided communicator lessened the burden of what that person would do "if I wasn't there". For most of society, these threads that allow access to life, friendship, independence, safety, choice, and purpose are inherently assumed. Our participants shared how they advocated for these same essential tenets.

A service provider (SLP) emphasized the importance of informal support to foster the use of AAC by explaining how the capabilities of communication partners can be taken into consideration during assessment and trial. "We are evaluating them as communication partners as well, not just the child [who uses AAC]. The idea is to see if the team can handle all the tasks and responsibilities that come with teaching a child to use the device." As stated by another SLP, "you never want to make it impossible for [the family] to implement [AAC] at home."
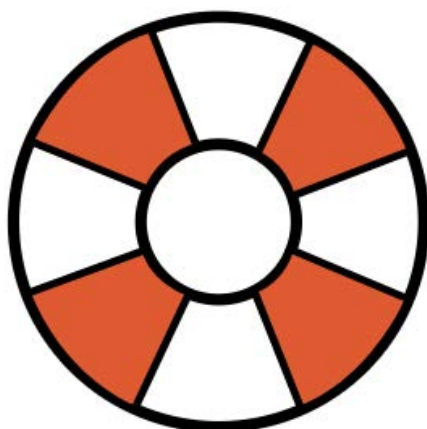
Supports

"When there's a level of confidence that you're hearing the individual's true voice, that's my highest measure of success."

AAC assessment

Factors that relate to AAC systems
Technology issues were common for AAC systems. The participants indicated breakage and maintenance could lead to abandonment if a person or their support system could not manage the technology design or user needs. For some, minor dysfunctions might mean they are without a means to communicate until the issue is resolved. A service provider (an SLP), noted how malfunctions could impact AAC use, recalling an experience in which a client discontinued use of an AAC system due to lack of technical support. The participant added, "It is nice when you do have support from the companies, but when you don't, it is extremely frustrating."

Individuals who use AAC systems noted how they need access to initial and ongoing professional support that is knowledgeable, experienced, and creative. Also, they mentioned that there should not be a "one-size fits all" solution to AAC design. Caregivers noted that often they were expected to make choices with little or no knowledge of options. One caregiver spoke on the lack of adaptability in AAC designs: "She is a two-switch user, my daughter is a shaker and a mover. Just because scanning is not the big thing right now, [eye-tracking] just did not work for her, right?"

"She is a two-switch user, my daughter is a shaker and a mover. Just because scanning is not the big thing right now, [eye-tracking] just did not work for her"

Depending on the device, AAC systems can use a variety of input methods to achieve the same objective on the same device. Mainstream technology, such as smartphones and tablets are less likely to meet an end-user's specific needs over a multipurpose technology such as web browsing, which can be developed into a customized solution.

## Aspects that influence interaction with technology

The building of stronger social supports is enabled using aided communication tools. Social media and peer networks of online support are adding meaning and value to the lives of many who struggle with "fast enough" aided speech to participate fully in conversations held face-to-face.

technology

AAC flexibility refers to the options, either integrated hardware or software, that allow for adjustment enabling technology to work effectively for a wide range of needs. From the perspective of access, this concept includes limited device pools, the effects of one-size-fits-all technology, and company monopolies. Technicians described their experiences with the limited effects of flexibility on AAC selection and successful implementation, while the manufacturer argued that lots of flexibility has a tendency to overwhelm clients because "they don't actually know what to do with it". One technician emphasized the importance of client-specific device flexibility despite lacking the resources for it, stating "you get creative, you find a way".

A key contributor to effective interaction with technology is the education of all stakeholders including the client, the family, and the providers. It is important to seek "in-depth" communication, with the manufacturer asking, "how can [clients] take part in actual conversation". One technician emphasized the importance of training clients for future success explaining, "I want to give [clients] the tools to do it".

According to technicians, limited flexibility of AAC hardware and software leads to client frustration and high abandonment rates when relying on limited device pools and fixed trial periods. For the manufacturer, limited software flexibility and single-platform compatibility of AAC applications allows for more successful implementation for AAC professionals and clients overwhelmed by flexibility.

Clients reported that one of the factors that influences the quality of the experience with AAC systems includes the quality and variety of voices used by speech generating devices, as well as the volume. For example, depending on the end-users' age, level of development, and cognitive abilities, a slower-paced voice may become frustrating over time as there is a larger delay before the intended message is communicated.
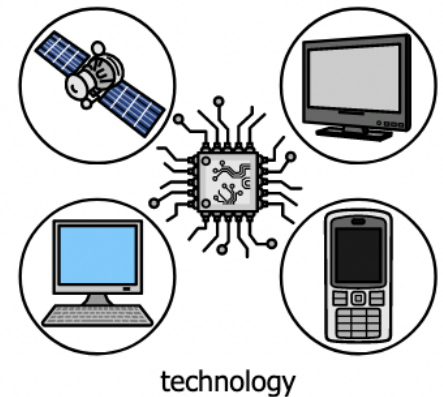
Service Delivery

The findings revealed multiple aspects of AAC service delivery and professional practices that influence the selection and use of AAC in Canada. As found in previous studies of AAC services in other countries, there is significant variability in AAC service delivery in Canada based on factors such as the age of the individual who uses AAC [51], funding, practice setting [52], policy [53] and service provider education and experience [54]. The findings suggest a need for more resources in AAC service provision, including funding, trial equipment, and specialized personnel to provide equitable and comprehensive service. One participant spoke on the need for adequate examination and comprehensive iterations: "There's a lot of assessment that needs to happen before you use the technology".

local AAC service

Some service provider participants spoke about challenges in services that impact access to AAC such as waitlists and lack of equipment. One service provider, an SLP, explained that "we can't go through trials fast enough and we don't have enough equipment in order to service everyone." Another SLP said, "kids are waiting, even though they have some skills and they're interested and ready but there just isn't the pool of technology to loan or the library for those sorts of [AAC systems]." Speaking to how physical location impacts access to AAC, one participant, an OT, explained, "for clients specifically looking for high tech systems, it can really be limited to where they're located geographically. If they're not in any catchment of these expanded level clinics, they may just not be eligible based on their postal code."

Starting with low or light tech devices before moving towards end-user interactions with high tech devices and having an efficient plan for measuring satisfaction can aid in supporting users to select an appropriate technology. It is important to have a team-based approach when decision making and service assessments. Factors that influence the effective delivery of AAC systems include access to online and phone services, having more informed selection or prescription of technology through funding services and school offerings, the implementation of technical support, having a way to measure effectiveness of the AAC system, and the continuity of service including assessment, implementation, and technical support.
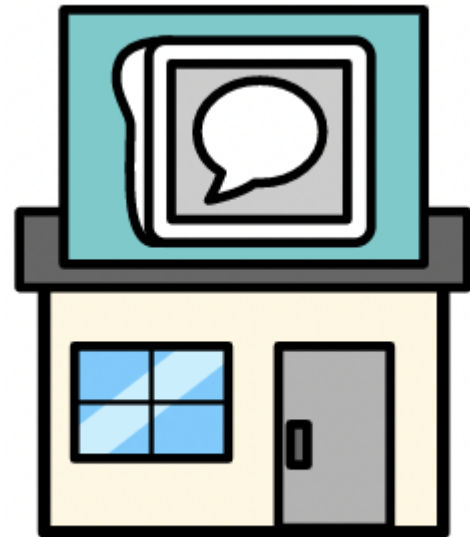
AAC systems and Services

Participants emphasized the importance of collaborative and coordinated support among key stakeholders to facilitate access and use of AAC. Team-based practices among service providers are common to AAC services [41, 55-57], however, as indicated by participants, facilitating the use of AAC requires involvement beyond service providers. This study highlighted the importance of familial support in AAC intervention. This signifies the importance of using family-centred approach, including the development of a collaborative relationship between parents and service providers [58, 59].

relate

AAC

One service provider, an OT, explained how they work as part of a team throughout the process, from provision to implementation of AAC. "We're involved in setting up a device and training a team, and then we're there to support [the team]." Another participant explained that collaboration supported consistency, "the school and the home team collaborate to build parent capacity and also [to make] sure that we're dealing with the same AAC set up in both environments."

Participants spoke of the complexity of AAC assessment which involves weighing factors related to the AAC system, the individual who uses AAC, and the interaction within their environment. Participants felt that a positive relationship between the individual and their AAC system promotes effective use of AAC and that facilitating this relationship through assessment, recommendation, and intervention is central to AAC services.

One service provider spoke about the lack of training specifically for the adult population. "The community service team out here, we are super invested and wanting to help people live great lives in their community, we don't have the training. When these people are younger, families work with the speech therapist. Adults in Ontario don't get that funding for therapists, they only get funding for front line services. And the front-line service people aren't therapists". This highlights the challenges faced by community services when providing support for individuals or caregivers who use AAC systems or services. The lack of funding for the adult population creates a barrier when accessing these services.

Another important factor identified by participants is the access to AAC systems for testing and training before purchasing these devices (even if limited to older devices). Practice and trial evaluations enable individuals and caregivers to make informed decisions about the systems and increase the chance of successfully integrating the system into their lives.
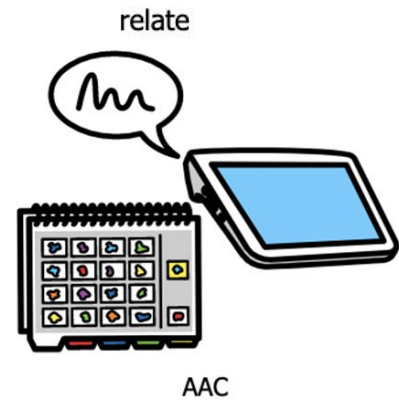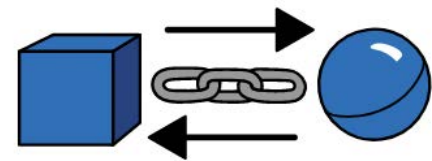
Environment (physical, school, social)

Environmental factors impacted the effective use of AAC devices. Participants noted how their devices rarely worked effectively in all the different life situations and environments they required. Individuals and caregivers both stressed that healthcare and emergency situations were particularly frustrating and unsuccessful when using aided communication, due to the speed needed and the lack of trained healthcare personnel. In these situations, it fell on the caregiver to "become their voice".

Physical Environment:

The use of an AAC system needs to be effective in both a noisy environment and a quiet environment (such as a movie theatre). Primary systems that might be very successful at home or school may not work outdoors, with fluctuating light, noise, and access to power. AAC systems are subject to failure "No matter the device, there's always the risk of damage impacting how it's being used".

School Environment:

The school environment provides important opportunities for communication and participation and was a focus for intervention for many service providers. One service provider, an SLP, reported challenges supporting AAC within the school environment stating, "when children are in large classrooms and there is one EA to take care of you know, five, six children with different needs, many times modeling [AAC] is not realistic … it requires a lot of time and effort." The influence of school staff was another factor in AAC use. An SLP explained, "I would say that the comfort level of school staff was a huge indicator [of success] ...when we started, no one wanted to touch anything, and now they're able to self-generate ideas and just really be better communication partners supporting the students."

Social Environment

The goal of caregivers and service providers is to attain unwavering belief in confidence of person who uses AAC (the partner removes themselves from the interpretation allowing the person who uses AAC to act independently). One user of AAC systems has remarked on the impact of being able to communicate independently through these systems. "[AAC system] has changed my life. I was lonely and had given up on a good future, but now I feel loved by many loving people because I can talk with them". Access to AAC systems enables users to communicate with individuals who are unfamiliar with their communication method, thereby providing them with the opportunity to fully express themselves.

### Financial aspects

Funding-related issues were inconsistent. While the initial costs for an AAC device were often covered, costs of repair and maintenance of devices, as well as training for caregivers and support workers were often neglected or under-funded. Technicians described how a lack of funding and manpower leads to the prioritization of either adapting devices to attempt to meet clients' needs or training clients on implementation. One technician stated, "I'm a one-man show too so... I just don't have the time for it". The


financial service

manufacturer emphasized the complications of maintaining revenue while supporting clients in an industry with a high social impact. They explained, "we're faced with a choice as a manufacturer of do we just keep promoting the same thing and have the only way that we can financially keep doing that is just to keep selling more and more and more".

Many service providers reported government funding as a source of financial support for AAC, however commented on its limitations, especially inconsistency across provinces. One participant noted that funding for the system itself is not the only component, there is a need for funding for structures that support attachment to AAC systems. "A lot of the really good mounts costs a lot of money. A lot of mounts aren't covered with a lot of funding sources and some of these folks need things in a very specific location in order to be able to use them." Without funding, the cost of AAC systems may be prohibitive for some. One service provider, an OT, stated, "We always have to be very cognizant of what we're prescribing and how much of a financial impact or financial burden that might have on a family."

All manufacturers and technicians emphasized a need for educating AAC invested partners. Lindsay state that "clinicians feel unprepared to recommend, provide and train assistive devices for young children because they have often not received adequate academic preparation to provide such services" [41]. Giving clients access to communication requires not only educating clients on successful implementation but also educating other AAC stakeholders to encourage clients to mentor others. Successful AAC implementation is a result of many smaller instances of success and an accumulation of understanding that includes encouragement from a client's support network. Manufacturers and technicians argued that
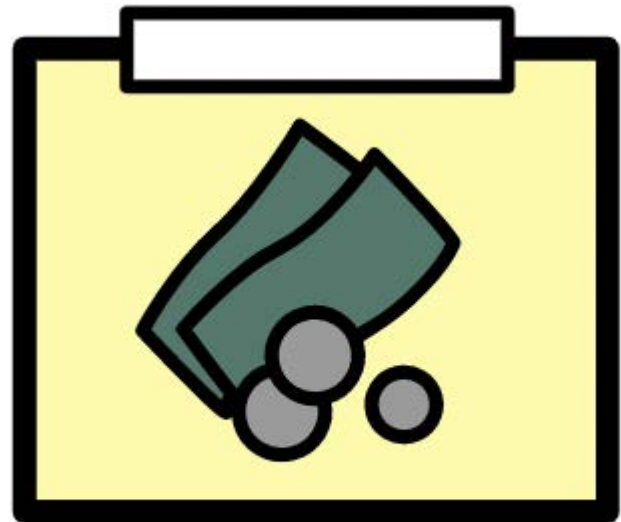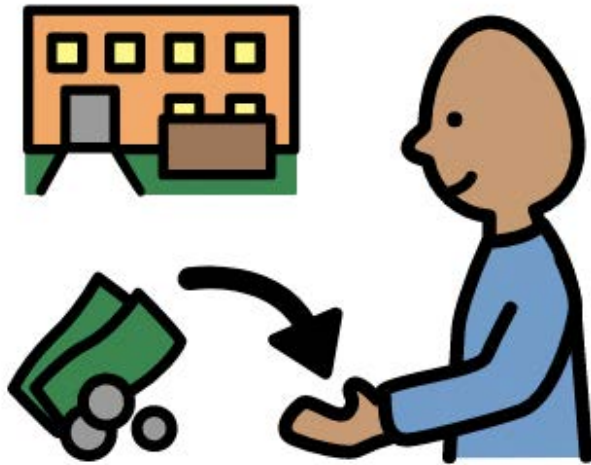
financial aid

funded access to communication should not be based on pre-existing assumptions of intelligence, education, or limited by age.

Client support must be inclusive such that funding must be obtained from charities and government organizations to meet specific client needs, training, and the education of the client and others about AAC. A lack of funding presents barriers. Two technology technicians indicated that they must prioritize different aspects of client success. Although creative solutions allow flexibility with a limited budget, less time can be allocated to training clients in device implementation, or altering devices to client specific needs. Flexibility and implementation are both important, so attempting to prioritize leads to less cohesive and individualized integration of AAC.

> We always have to be very cognizant of what we're prescribing and how much of a financial impact or financial burden that might have on a family

right

Human Rights Issues

Participants using aided communication felt passionately that each person has the right to a voice of their own and a right to be heard. They advocated for these rights to be supported by a society that promotes the universal rights of all to autonomy, choice, safety, and utility but that often falls short for individuals experiencing the greatest exclusion. They iterated that to be robbed of a voice is to be denied access to life. The UN Convention on the Rights for Persons with Disabilities (UNCRPD) promotes the rights of autonomy, safety, social participation, and communication as universal. The perspectives of individuals using AAC, as well as their caregivers in our study closely align with the legitimacy of these goals. The findings highlight the need for enhanced accessibility to AAC systems and services to support Canadians who require alternative modes for communication and aid in decreasing the vulnerability which is often accompanies users of AAC devices. Service providers also recognized the value of AAC to protect the rights of people with complex communication needs. As stated by one participant, an SLP, "The goal is communication, and the forum shouldn't matter. We all know that it's a basic human right...that's why we're so invested in doing this and passionate about [AAC]."

"The goal is communication, and the forum shouldn't matter. We all know that it's a basic human right...that's why we're so invested in doing this and passionate about [AAC]."

DELPHI SURVEY

From the focus groups, the themes identified led to statements that identify the key criteria expectations for AAC Systems. One hundred and forty statements were chosen to be representative of the information collected in the focus groups. These consensus statements were developed into an online survey housed in Qualtrics (Appendix 1). The survey was randomized such that each of the sets of questions related to the themes as identified in the previous section were displayed in different orders. This allowed us to collect information from all participants in such a manner that bias was minimized as a result of question presentation and fatigue of the individual. Respondents ranked the items on a 9-point scale (1-3 will indicate low importance, with 7-9 being extremely important). Since a Delphi study is based on consensus, components were considered as strong indicators of importance if they were rated 6-9 on the scale by more than 60% of the population of interest.

Given that the populations answering the survey ranged from persons who use the technology as their primary means of communication, across to manufacturers of that technology, we expected some variability, leading to the choice to include 60% consensus. Those statements that achieved consensus are listed in Table 6[2]. Recommendations for services to support persons who use AAC systems can now be developed.

Table 6: Final Round Delphi Statements (themes were randomized for each participant)

Financial aspects financial service	b) Funding for training and education for: 　　　b. families/caregivers 　　　c. service providers 　　　d. educators e) Cost of buying or leasing the AAC technology
Physical Environment environment	c) The need to use the AAC systems at school e) The need for the AAC system to be used in a noisy place (restaurant, public spaces). g) To have unrestricted access for spaces/places in which the AAC system can be used. h) Effective physical access (positioning and mounting)
School	c) Access to rehabilitation professional supports (SLP, Rehab Therapy, OT…) e) Availability of knowledgeable and trained teachers in AAC g) Early introduction of AAC system

[2] These Delphi statements are numbered based on the order of the original survey. Please refer to appendix 1 for the full and complete survey.

Table 6 (continued): Final Round Delphi Statements

Social Environment
 social
	a) The AAC system must allow the user of AAC systems to communicate with people who are not familiar with their methods of communication.
	 b) When working with communication partners it is important to have:
	    b. Competency of partner (a person who is familiar with the system and interaction techniques of the user).
	    e. Discovering abilities (the importance of letting the AAC user express themselves completely).
	    f. Unwavering belief in confidence of person who uses AAC (the partner removes themselves from the interpretation allowing the person who uses AAC to act independently).

AAC systems and Services AAC	b) Access to AAC services. g) Having access to AAC systems for testing and training before buying the device (even if these are limited to older devices).
Societal Attitudes society	h) How impatience of society affects interactions and communication. j) How societal attitudes towards technology (fear, comfort) affect interaction by persons who use AAC systems. k) How persons who use AAC systems are held to different standards as compared to others. l) How legitimacy of pre-programmed message is questioned by members of the society. m) How feeling like a burden affects persons who use AAC systems. p) How persons who use AAC systems are thriving vs surviving (surviving includes ability to order meals, ask to use the washroom while thriving allows expressions of interest and independence).
Informal and Formal Supports Supports	a) Family. c) Collaboration among supports (in provision and/or implementation of AAC). e) Role models/mentors.
Goals target	b) Relationship-building (friendships, partnerships). c) Dreams for the future/Life-related Goals. e) Achieve meaningful communication (as compared to meeting basic needs like food requests). f) Expression of emotion. g) Promotion of independence for the person who uses AAC systems. h) Safety. i) Social belonging. j) Autonomy (ability to act on one's own values or interests). k) Contribution to Society.

Table 6 (continued): Final Round Delphi Statements

Interaction with technology	b) time and effort to produce messages. f) Strategies for ease of communication. h) Having a back-up option. i) Features that allow the communicator to correct errors (in typing or selection of specific icons).
Personal	b) Sensory processing. c) Fatigue. e) General Health. f) Literacy. g) Personal preferences (for AAC).
Human Rights	b) Decreasing vulnerability with AAC. d) Communication as a basic human right.
Service Delivery	b) Starting with a device that is low/light tech before moving to interaction with a device that is high tech. c) Online/phone services available. g) Team-based approach (I.e. family and multi-disciplinary). h) Informed selection/prescription of technology (based on features, funding, school offering, etc.). i) Having a way to measure if the AAC system was helpful or successful. j) Ongoing support. k) Family involvement in decision-making. l) Continuity of service from assessment, implementation to technical support.

Discussion

The online survey allowed us to better gauge the importance of various aspects of AAC systems for all members of the community. The answers can provide researchers and members who are developing guidelines for the development of requirements for AAC systems with evidence-based information about the importance of aspects related to AAC systems and services. Moving forward, we must consider the themes that are representative of the most important needs of the persons requiring aided communication. These have been identified from iterative feedback of persons who use the technology, caregivers and support partners who assist with communication, and service providers within the community who evaluate and implement the technology within a network of the client's social circle to enable effective communication.

RECOMMENDATIONS

This research included different strategies to approach communication and access to systems (AAC systems, provider systems, social systems etc.). The landscape of AAC communication tools for use in employment and the methods of evaluation and assessment for the technology were originally reviewed. The current status of integration of persons with disabilities into the Canadian government workforce was evaluated. An examination of access to the technology from the perspective of "if I am a Canadian who requires a form of AAC, how can I gain access?" was evaluated. These two pilot studies were followed by interviews and focus groups to ensure that the "voice of the consumer" was heard. Themes of importance were drawn from the rich discussions of the persons who are most familiar with the AAC systems and developed into a series of statements. These statements were presented back to members of the community through a Qualtrics survey to achieve consensus on those most important in the development of guidelines for better integration. The recommendations resulting from this iterative feedback are presented.

General

- Clarification is required distinguishing between Accessible Canada Act [42] section 5.c "information and communication technologies" and 5.c(1) "communication, other than information and communication technologies". As an example, accessible websites are listed as actions taken under 5.c(1) rather than 5.c. According to the visual representation of the ACA [47], "Communications," presumably referring to section 5.c(1), means "Barrier-free services and spaces for persons with communication disabilities".

Assessments

- There is a need to standardize the definitions of the descriptive traits used in the assessment of personal abilities, environmental characteristics, potential assistive technology, and contextual factors.
- Development of an assessment model or assessment models tailored specifically to individuals who may benefit from AAC is needed which is rooted in existing theories, research evidence, and the experiences of those in the AAC community.
- Future assessment models should include clearly defined measurable outcomes related to assistive technology provision.
- An expansion of candidacy for AAC – a need to allow access prior to proof of successful short-term outcomes.

- Establishment of a better means of allowing equal access across Canada (large disparity among provinces).
- Increase access to training devices that can be used on short- and medium-term loans.

Training

- Increased funding for both training and access to devices.
- Increased training to all stakeholders including family members, communication partners, service providers, and persons who use AAC.

Access to AAC systems and technology within Canada

- Websites should adhere to WCAG 2.0.
- Flesh-Kincaid reading levels must be assessed and implemented at a level of 75 for all websites.
- Systems should be designed to be able to be used universally – home, school, hospital, noisy environments, outdoors, indoors.

AAC Services

- Practice guidelines are needed to guide equitable AAC assessment and intervention across Canada.
- Professionals require opportunities and support to engage in ongoing training, education, and networking to stay current in the field of AAC.
- Collaborative approaches among AAC professionals, people who use AAC and other key stakeholders such as family are critical given the complex nature of AAC assessment and intervention.
- Funding and service-related policies vary across Canada and can both support or restrict access to AAC systems. Service providers input is needed to improve policies relevant to the provision of AAC services and systems.

Employment

- Facilitators to employment include personal strengths, access to technology, and supportive relationships.
- It would be beneficial to increase supports in the areas of career preparation, training, and transition to adulthood.
- The same modules developed for post-secondary institutions could be implemented for employment settings.

- For small businesses or private sector, funding should be provided as an incentive for employers to train staff and make their setting more accommodating for potential employees using AAC.
- All entities within the Canadian Public Service should be required to submit a thorough reporting of all actions, initiatives and challenges related to accessibility, inclusion and employees with all types of disabilities, including speech and communication disabilities.
- Further research into including and accommodating people with speech and communication disabilities within the Public Service is needed.

Schooling

- Early intervention with the use of AAC systems is important to sustained learning.
- Development of guidelines for school-aged children using communication aids to support consistency of support personnel in school settings.
- Prioritize educational assistant positions with specialized training, such as speech and language assistants and persons who provide consistent care to children with communication aids.
- Establishment of a post-secondary communication support personnel familiar with basic communication devices use - letter boards, device use.

Healthcare Settings

- Extend language translation services to people who use communication aids to allow for the same provision of service.

Social Environments

- Support systems (partners, caregivers etc) are invaluable in the successful. implementation of AAC system use. These persons should be recognized and trained to avoid abandonment of devices.

AAC Systems

- Flexibility is required in applications to allow for changes and modifications by people familiar with the system.

PUBLICATIONS RESULTING FROM THIS RESEARCH

For additional information about the research conducted as part of this project, please see additional publications as listed below.

Conference Publications

S. Burnham, T.C. Davies, S. Pinder, B. Batorowicz. Mitigating Midas Touch: How Graphic Symbol Semantic Distance Influences Eye-Tracking Usability. *International Society for Augmentative and Alternative Communication (ISAAC)*, July, 2023.

S. Bonar, S. Burnham, S. D. Pinder, B. Batorowicz, C. Davies. Manufacturer Perspectives on the Design and Use of Augmentative and Alternative Communication. International Society of Augmentative and Alternative Communication. July, 2023.

J. Henderson, S. D. Pinder, B. Batorowicz, C. Davies. Barriers to accessing augmentative and alternative communication (AAC) technology in Canada: A Scoping Review. International Society of Augmentative and Alternative Communication. July, 2023.

G. Watson-Hyatt (invited panel speaker), Equity in Communication: Accommodating People with Communication Disabilities in the Workplace, *Durham Accessibility Conference,* May, 2023.

S. Burnham, S. D. Pinder, B. Batorowicz, T. Shepherd, C. Davies. Mitigating Midas Touch: How Icon Parameters Influence Eye-Tracking Usability, *Assistive Technology Industry Association*. February, 2023

D. McEachern, T., Shepherd, J. Henderson, S. Bonar, S. Pinder, T.C. Davies, B. Batorowicz. The key areas of effective design and use of augmentative and alternative communication: Exploring first-hand accounts of young adults and their caregivers. *Assistive Technology Industry Association.* February, 2023

G. Watson Hyatt. Equity in Communication: Workplace Universal Design *Disability and Work in Canada 2022 Virtual Conference*. Nov/Dec 2022.

S. Lackey, S. Burnham, G. Watson Hyatt, T. Shepherd, S. Pinder, T.C. Davies, B. Batorowicz. Perspectives of AAC service providers in Canada on factors influencing effective use of AAC technology. *Communication Matters International AAC Conference*, September, 2022

J. Henderson*, S. Blahey, S. D. Pinder, T. Shepherd, B. Batorowicz, C. Davies. Usability evaluation of application forms for augmentative & alternative communication (AAC) technology in Canada. *Rehabilitation Engineering Society of North America (RESNA)*, July 2022. *winner of the Student Scientific Paper Competition.

S. Burnham, P. Finak, J. Henderson, N. Gaurav, T.C. Davies, S. Pinder, B. Batorowicz. Models and frameworks for guiding assessment for aided Augmentative and Alternative Communication (AAC): A Scoping Review. *International Society for Augmentative and Alternative Communication (ISAAC)*, August, 2021

S. Lackey, G. Watson Hyatt, S. van Engelen, S. Li, T.C. Davies, S. Pinder, B. Batorowicz. Barriers and Facilitators to Implementing Workplace Accommodations for Adults who Require AAC: A Systematic Review. *International Society for Augmentative and Alternative Communication (ISAAC),* August, 2021

P. Finak, S. Burnham, J. Henderson, N. Gaurav, S. Pinder, T.C. Davies, B. Batorowicz. Models and frameworks for guiding assessment for aided Augmentative and Alternative Communication (AAC): A Scoping Review. *2021 Rehabilitation Research Colloquium, Queen's/McGill University,* May, 2021

Journal Publications

S. Lackey, G. Watson Hyatt, B. Batorowicz, S. van Engelen, S. Li, S. Pinder, T.C. Davies. (2023). Barriers and facilitators to accommodations in the workplace for adults who use augmentative and alternative communication (AAC): A systematic review. Augmentative and Alternative Communication. doi:10.1080/07434618.2023.2170277

S. Lackey, S. Burnham, G. Watson Hyatt, T. Shepherd, S. Pinder, T.C. Davies, B. Batorowicz. (2023). Perspectives of AAC service providers in Canada on factors influencing effective use of AAC technology. Communication Matters (in press).

S. Bonar, S. Burnham, J. Henderson, B. Batorowicz, S. D. Pinder, T. Shepherd, T.C. Davies Canadian Manufacturer and Technician Perspectives on the Design and Use of Augmentative and Alternative Communication Technology" to Disability and Rehabilitation: Assistive Technology. (accepted with minor revisions)

S. Burnham, P. Finak, J. Henderson, N. Gaurav, B. Batorowicz, S. Pinder, T.C. Davies. Models and Frameworks for Guiding Assessment for Aided Augmentative and Alternative Communication (AAC): A Scoping Review. Disability and Rehabilitation: Assistive Technology TIDT-09-2022-017. (submitted)

Lackey, S., Burnham, S., Watson Hyatt, G., Shepherd, T., Pinder, S., Davies, T. C., & Batorowicz, B. (2023). Influential factors on effective use of augmentative and alternative communication (AAC): Perspectives of AAC service providers in Canada. Augmentative and Alternative Communication. (submitted)

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APPENDIX 1: INITIAL ONLINE SURVEY

To explore the key areas of importance with respect to the effective use of technology for AAC.

ALL ITEMS RANKED ON A 1-9 scale where 9 is the most important

Please rate the importance of the following financial aspects.

   a) Funding for communication systems
   b) Funding for training and education for:
          a. person who uses the device as the primary means of communication.
          b. families/caregivers.
          c. service providers.
          d. Educators.
   c) Funding for assessment and implementation services.
   d) Requirement to meet specific funding criteria.
   e) Cost of buying or leasing the AAC technology.
   f) Burden of high costs to person who uses AAC/family.
   g) Please provide any additional comments about financial aspects with respect to AAC systems. (OPEN QUESTION)

Please rate the importance of the following needs related to places or the physical environment.
   a) To be able to use the AAC systems at the hospital.
   b) The need to use the AAC systems at home.
   c) The need to use the AAC systems at school.
   d) The need to use the AAC systems in unfamiliar settings.
   e) The need for the AAC system to be used in a noisy place.
   f) The need for the AAC system to be used outdoors (sunlight, rain, cold).
   g) To have unrestricted access for spaces/places in which the AAC system can be used.
   h) Effective physical access (positioning and mounting).
   i) Please provide any additional comments about how your AAC systems are used within specific environments. (OPEN QUESTION)

Please rate the importance of the following aspects of the school environment.
   a) Availability of the same AAC system at home and at school.
   b) Consistency of use of AAC systems between school and home.
   c) Access to rehabilitation professional supports (SLP, Rehab Therapy, OT…).
   d) Knowledge of rehabilitation professionals about AAC (SLP, Rehab Therapy, OT…).
   e) Availability of knowledgeable and trained teachers in AAC.
   f) Availability of educational assistants' support.
   g) Early Introduction of AAC system.
   h) Please provide any additional comments about using AAC systems within the school environment. (OPEN QUESTION)

Please rate the importance of the following aspects of the *Social Environment*

a) The AAC system must allow the user of AAC systems to communicate with people who are not familiar with their methods of communication.
b) When working with communication partners it is important to have:
   a. Consistency of partners.
   b. Competency of partner (a person who is familiar with the system and interaction techniques of the user).
   c. Reliable relationship/bond.
   d. Understanding of emotional and impulse regulation (an ability to understand how the user of AAC feels while they are communicating with their AAC system).
   e. Discovering abilities – the importance of letting the AAC user express themselves completely.
   f. Unwavering belief in confidence of person who uses AAC (the partner removes themselves from the interpretation allowing the person who uses AAC to act independently).
c) Please provide any additional comments about using AAC systems within the social environment. (OPEN QUESTION)

Please rate the importance of the following aspects of the *Systems*

a) Time on waitlist to receive the AAC system.
b) Access to AAC services.
c) Rural access to AAC services and systems.
d) Urban access to AAC services and systems.
e) Access to AAC services and systems in all geographical areas.
f) Flexibility of health/education systems to meet communication needs of the user of the AAC system.
g) Having access to AAC systems for testing and training before buying the device (even if these are limited to older devices).
h) Please provide any additional comments about access to AAC services and systems. (OPEN QUESTION)

Please rate the importance of Societal Attitudes

a) Understanding how societal attitudes affect the use of the AAC systems.
b) Knowing that members of society understand competence of persons who use AAC systems.
c) Individual beliefs of people in society affect the ability to interact using AAC systems.
d) Societal myths exist that affect interaction with others.
e) Bias from others is a concern.
f) Misconceptions about persons who use AAC systems affect them (me).
g) Underestimating cognitive ability is common.
h) Impatience of society affects interactions and communication.
i) Belief in the use of AAC (buy in) is necessary to be effective.
j) Attitudes towards technology (fear, comfort) affect interaction by persons who use AAC systems.
k) Persons who use AAC systems are held to different standards as compared to others.
l) Legitimacy of pre-programmed message is questioned by members of the society.

m) Feel like a burden is common by persons who use AAC systems.
n) System bias and prejudice prevents effective communication using AAC systems.
o) Acceptance of AAC as a form of communication.
p) Thriving vs surviving is important for persons who use AAC systems (surviving includes ability to order meals, ask to use the washroom while thriving allows expressions of interest and independence).
q) Please provide any additional comments about societal attitudes with respect to AAC systems. (OPEN QUESTION)

Please rate the importance of the informal and formal supports

a) Family.
b) AAC Service Providers.
c) Collaboration among supports (in provision and/or implementation of AAC).
d) Having a person to assist communication with others (i.e., using a low-tech display).
e) Role models/mentors.
f) Supports that allow independent communication using AAC systems throughout adulthood.
g) Transitions throughout childhood (school entry, changing schools).
h) Professional development for educators and services providers.
i) Please provide any additional comments about informal and formal supports with respect to AAC systems. (OPEN QUESTION)

Please rate the importance of the following goals

a) Ability for persons with AAC to self-actualize (reach their full potential and life aspirations).
b) Relationship-building (friendships, partnerships).
c) Dreams for the future/Life-related goals.
d) Be able to use the AAC systems effectively and efficiently.
e) Achieve meaningful communication (as compared to meeting basic needs like food requests).
f) Expression of emotion.
g) Promotion of independence for the person who uses AAC systems.
h) Safety.
i) Social belonging.
j) Autonomy (ability to act on one's own values or interests).
k) Contribution to Society.
l) Please provide any additional comments about goals with respect to AAC systems. (OPEN QUESTION)

Please rate the importance of the following aspects that influence interaction with technology.

a) learning demands.
b) time and effort to produce messages.
c) Familiarity with the device.
d) Finding the right fit (ensuring that there is compatibility between the device and the person that allows for effective, efficient communication).
e) Ease of use for communication partners.

f) Strategies for ease of communication.
g) Accessories (carrying case, stand, mount).
h) Having a back-up options.
i) Features that allow the communicator to correct errors (in typing or selection of specific icons).
j) Please provide any additional comments about interaction with AAC systems. (OPEN QUESTION)

Please rate the importance of the factors related to the AAC systems

a) Reliability of devices (I.e., short battery life, device breakdown).
b) Support for device repair and maintenance.
c) Type of access methods – can you use a variety of input methods with the same device.
d) Low/light tech or no tech (Ie. printed boards, yes/no through eye movements).
e) High tech (speech generating devices, eye gaze, or brain computer interfaces for example.
f) Multimodal approaches (Ie. Using many different methods to communicate).
g) Availability of both old and new technology.
h) Technical support for both old and new technology.
i) Mainstream technology (like iPads or iPhones that are similar to everyone else).
j) Specialized technology (devices that can be programmed to meet specific needs).
k) Multipurpose technology (I.e. web browsing, texting in addition to communication).
l) Compatibility between hardware and software/apps.
m) Availability of software/apps on various platforms.
n) Access to subscription-based software/apps.
o) Durability.
p) Portability of the device.
q) Customized solutions.
r) Preferred manufacturers/vendors.
s) Voice of speech generating device – volume.
t) Voice of speech generating device – quality / variety.
u) Please provide any additional comments about factors related to the design of AAC systems. (OPEN QUESTION)

Please rate the importance of personal factors that affect interactions with AAC systems

a) Physical ability.
b) Sensory processing.
c) Fatigue.
d) Previous experiences.
e) Health.
f) Literacy.
g) Personal preferences (for AAC).
h) Please provide any additional comments about personal factors that affect interaction with AAC systems. (OPEN QUESTION)

Please rate the importance of addressing these Human Rights issues

a) Advocacy for AAC/people who require AAC.
b) Decreasing vulnerability with AAC.

c) Reducing marginalization of people who require AAC.
d) Communication as a basic human right.
e) Please provide any additional comments about human rights issues with respect to AAC systems. (OPEN QUESTION)

Please rate the importance of the following aspects of service delivery

a) Using Evidence-based assessment tools enables effective interactions between the user of AAC systems and the system.
b) It is important to start with a device that is low/light tech before moving to interaction with a device that is high tech.
c) Providing services remotely.
d) Having access to AAC service providers who only consult rather than provide direct interventions or supply AAC systems (I.e., no comprehensive assessment or implementation).
e) Collaboration among service providers.
f) Implementation (ongoing support, outcome measures, authorization).
g) Team-based approach (I.e. family and multi-disciplinary).
h) Selection/prescription of technology (based on features, funding, school offering, etc.).
i) Having a way to measure if the AAC system was helpful or successful.
j) Ongoing support.
k) Family involvement in decision-making.
l) Continuity of service from assessment, implementation to technical support.
m) Please provide any additional comments about service delivery with respect to AAC systems. (OPEN QUESTION)