# Understanding accessibility barriers and challenges for persons with disability

**NSHA Central Zone and IWK Health Centre's conversation with community organizations providing services for people with disabilities**

**November 2016**

**Compiled by: IWK and NSHA Central Zone Accessibility working group**

## *A. Introduction*

Access to services for persons with disabilities, especially patients, families, staff, physicians, volunteers, learners and all those who interact with our health system can come with unique challenges and barriers. World Health Organization [WHO] (2015) states that people with disabilities encounter a variety of barriers when accessing health care, which include: limited availability of services, physical barriers, health workers inadequate skills and knowledge. These barriers can impede full participation in one's own or a family member's care, affect routine navigation, and diminish social inclusion, thereby resulting in poor health. According to the United Nations' Convention on the Rights for Persons with Disabilities (2006) article 9.1, "State Parties should take appropriate measures to ensure persons with disabilities have access, on an equal basis with others, to the physical environment, transportation, to information and communications." To date the government of Nova Scotia's Advisory Panel on Accessibility Legislation has produced a report titled *Access and Fairness for all Nova Scotians* with recommendations that will act as drafting instructions for the new Accessibility Legislation expected to come in the near future. According to the report, the legislation will be an important step towards creating a barrier-free Nova Scotia with a lens focusing on access and fairness.

With a commitment to making our environment inclusive and welcoming, as well as aligning our efforts with the expected NS Accessibility Legislation, it is important to understand some of the barriers people with disabilities experience accessing our care services and ensure they are considered and accommodated in care services, work environments and physical infrastructure.

**The community conversation**

On June 3, 2016, 22 representatives from community organizations supporting people with disabilities and 22 staff from the IWK and NSHA Central Zone came together to have a conversation about barriers and challenges people with disabilities face when accessing our health care services. See Appendix A for list of participants.

Anne MacRae, Chair of the Disabled Persons Commission, gave an overview on the Access and Fairness for all Nova Scotians report. This was followed by a panel presentation of three speakers: Frank O'Sullivan - Executive Director of the Society for Deaf and Hard of Hearing Nova Scotians, James Hubley - employee of NSHA Central Zone, who has low vision; and Jo-Lynn Fenton, a parent of two sons on the autism spectrum disorder. Speakers shared their experiences in accessing health care services and programs.

After the panel presentation, participants broke into five small groups. This allowed for in-depth conversation on what is currently working well, barriers/challenges that exist, and suggested changes NSHA and IWK Health centres should consider for improvement. A significant number of the blind and low vision community could not participate in this conversation therefore a separate meeting was held with the Canadian Council of the Blind, Access and Awareness Nova Scotia Chapter on September 8, 2016. Their input has been incorporated into this report as well. Feedback captured in this summary report has been categorized in the below themes, which are

identified in the Access and Fairness for all Nova Scotians report as some of the areas of focus. Based on these themes the report will outline what is currently working well and what needs to be considered for improvements. Feedback is based on information shared by panelists and in small group discussions. The IWK and NSHA Central will independently come up with strategies and or action plans on how to address and or move forward on suggested next steps.

- ***Theme 1: Information and communication***

  This area of focus includes, but is not limited to: way finding signage, website and email communication, patient materials and forms translation, sign language interpretation, specific programs designed/developed for various communities.

- ***Theme 2: Design of public buildings and public space***

  This includes, but is not limited to: parking spaces, main entry doors to the buildings, consultation rooms' and washrooms' doors and spaces, room set-up, lighting, waiting room space, accessibility and accommodation in public spaces – e.g., cafeteria, lobbies.

- ***Theme 3: Attitudes and public education and awareness.***
  This includes education and awareness for staff. It is important to provide education and training on accessibility for staff to enhance their awareness and skills regarding working with people with disabilities. Partners could help with appropriate terminologies to use to be more inclusive.

## *B. What is working well:*

**Information and Communication**

Examples of positive practices included cards at front desks with directions to specific areas, some elevators with Braille panels and voice prompts, signage at IWK (especially bathroom access), and child-friendly distractors (such as children's television shows in waiting areas). Other positive features identified were NSHA TV monitors in hallways and elsewhere, hot spots throughout NSHA, tablet lending, phone numbers / email available for patient representatives, outpatient areas using vibrating alert systems, and pull systems and switches in consulting rooms that allow people alternative ways to alert staff.

***"Volunteers provide a wonderful support service"***

Volunteers provide a wonderful support service; for example, information volunteers at entrance desks who give directions and alert people to signage, walk individuals to appointments, etc. are highly valued. In general, participants expressed appreciation for flexible staff who take time to assist patients and families to navigate their way. Family and person centered care is helpful for those unable to advocate for themselves.

**Design of Public Buildings and Public Space**

Newer buildings and renovated areas in hospitals seem to consider universal design principles. These features were evident in family washrooms, areas that are well lit (natural daylight), clear signage to main building locations, and "pretty good" physical accessibility.

## *C. Areas for improvement*

**Information and communication**

Environmental Aspects

Participants expressed needs for a variety of communication options, such as:

- plain language (not medical terms) and visual cues
- sign language interpretation
- large print on patients materials and other communications
- phone texting to allow for easier appointment reminders for those who are deaf and hard of hearing
- augmentative / alternative means, including apps.

These options should be incorporated to the extent possible as part of signage, and provide alternative formats (Braille, audio, texting, electronic Word documents) for both preparation for medical encounters and follow-up information. Some participants also cautioned, however, that technology use (such as smartphone apps) requires resources, and entails costs that not all users can afford. Another caution was that self-service (technical) registration may be challenging to access for those who rely on people to ask questions. In addition, people who are deaf or blind may not be able to use the 'pick a number' registration process effectively, and touch screens are not accessible for those who are blind or have low vision.

Information about available interpretation resources should be shared with communities by various means. On-site screens can be used to promote Diversity & Inclusion, and to advertise resources and availability of mechanisms for feedback to the organizations.

An online video tour of the health centres would be helpful. GPS navigation and installed beacons (electronic devices) or trained site guides were also suggested as useful. Noise is a barrier for many people who have neuro-developmental sensory sensitivities or for those who are deaf or hard of hearing. The ICU uses a telephone to gain entry, or a call bell to request help. These systems are not accessible for those who are deaf or hard of hearing.

Signage in various languages could provide Braille, which should be at hand level. Use of symbols and pictures provides greater accessibility for some users. Signs should be brief and not overwhelming; too much signage can be confusing. Signs on black background with white lettering are preferred for those with low vision; both font and colour contrast should be considered. Braille, large and/or raised print should be considered in elevators to designate floor numbers, on doors numbers and washroom signs.

Timing of appointments matters to many patients / family members with disabilities. For

example, early appointments may not accommodate Access-a-Bus users. As well that appointments occur on time is important to reduce the emotional stress some may experience in waiting.

It was also suggested that in pre-op, care providers be informed if a patient is blind, for instance, and that patients be asked what will make their stay more accessible.

A range of experiences, both positive and negative, were reported for the transition from IWK to NSHA. Examples include the observations that information does not flow from IWK, and that youth "disappear" after transitioning to NSHA. In the view of some, these systems don't communicate with each other. Further to the issue of transition, other participants noted that some health services also end when transitioning to the school system.

Personnel Aspects

Volunteer patient navigators would strengthen way-finding and information provision. Also, consider providing personal care support; for example, some people need help changing into examination clothing.

Patients with disabilities need more time with NSHA professionals (as at IWK). It would be helpful for those booking appointments to be informed that if extra time is needed, it can be accommodated. Providing caregivers with details of what will happen at appointments is important to give them the information needed to prepare means of anticipating and managing patients' emotional distress (such as visual supports, scripts, conversation). This was mentioned specifically for those with a diagnosis of autism spectrum disorder.

Health care providers should avoid using figures of speech when working with people with intellectual disabilities / autism spectrum disorder; e.g., "Jump on here." Such instructions could be taken literally, causing anxiety for the patient.

English literacy requires consideration for deaf individuals who may use sign language as their first language, and may encounter stigma when they cannot use English fluently.

Summary of areas of improvement:

- Use a variety of communication options to share information in preparation and follow-up appointments
- Technical barriers such as use of registration kiosks, telephones, call bells or pick-a-number process for registration can be barriers for blind, low vision, deaf and/or hard of hearing patients
- Ensure timing, length and preparation of appointments meet the needs of people with disabilities
- Improve signage and way finding methods as suggested above
- Transition from IWK to NSHA is difficult and needs to be improved

**Design of public buildings and public spaces**
Participants suggested several areas where things could be improved with design and building spaces. One suggestion was the need for more accessible parking, including increased number of designated spots and space to accommodate vehicle ramps.

Greater consideration for universal design principles should also be given in the following spaces inside our facilities:

- Main entrances – marked clearly by signage, automatic doors and ramps and thresholds to code.
- Clinical areas – sufficient seating and space for all users with adjustable seating options.
- Washrooms – accessible doors, sufficient clearance for wheelchair users, sinks, soap and paper towel dispensers at an accessible height for all users.
- Cafeterias – seating options and height adjustable or tables at differing height to meet the needs of all users.

In addition to the suggestions listed above, participants also said that there need to be more flexible options for publicly accessed spaces, including different-sized seating and seating that can be moved/rearranged and height-adjustable tables/work surfaces, options for adjustable lighting in all patient access areas, employee offices, and ensuring all areas adhere to scent-free policy.

<u>Summary of areas of improvement</u>:

- More accessible parking
- More accessible washrooms, adjustable tables, automatic doors and ramps

**Attitudes and Public Education and Awareness**
Four key themes came out of the discussion – language used, need for professional development, need for changes in attitude, as well as interest in working collaboratively.

i. Use of Language

***The use of proper terminology to refer to a type of disability would be appreciated***

Comments from various speakers suggested that there are connotations and words used that are demeaning to those who have disabilities. The use of proper terminology to refer to a type of disability was discussed in the small groups when participants said that staff members need to learn more about proper terms. For instance, it was said that the "r" (*retard, sic*) word is being used at times in the hospital setting. It was also said that language needs to be more inclusive and the following suggestions were made:

- Do not refer to adults as children
- Speak to the patient first, and address him/her as is age-appropriate
- Stop using the word "sitter"
- Use terms like; different ability, special needs instead of handicapped and mobility accessible

ii. Knowledge/professional development

In all small group discussions, participants talked about the need for more training and professional development for service providers, especially the need for staff to learn more about the various intellectual and physical disabilities that exist. Family members expect service providers to know more about disabilities. One group talked about the lack of professional development opportunities available to staff, and one staff member gave the example of having to take a vacation day to participate in this event as their manager thought it to be unrelated to their work.

***"It's important to see an individual as a person first before their disability"***

There is a feeling that not all practitioners are aware of the various disabilities and that much expertise is not shared between departments/services.

It was raised that the emergency department employees in particular should at least have knowledge of various intellectual and physical disabilities in order to know how to accommodate the person. One participant said that oversights and deaths happen due to attitudes and lack of awareness. The emergency department should be a priority for education on autism spectrum disorder, for instance (Note: this is the focus of a current TRIC grant). Many individuals with autism spectrum disorder show pain in different ways and there are many stories of patients being either turned away because they are seen as having a behavioural problem that should be managed by the parent, or they are not provided with potentially life-saving tests. Another example provided was of an emergency room physiotherapist not knowing how to address symptoms/problems that are attributed to spina bifida. Education for frontline staff was also said to be key.

A participant also gave an example of staff not knowing what a white cane means. If there is more awareness people would be more cognizant that when they see someone with a white cane wandering or walking towards them, they should make sure that a clear path is available. Hospital staff should also announce who they are when they enter a room of a patient who is blind or has low vision and speak directly to the blind or patient with low vision, not to the person with them.

Education should be extended to food services employees on how to deliver food especially for blind or patients with low vision. There are cases where food is left open in trays without the patient knowing it is there as no one has informed them. Including accessibility needs when taking patient history or doing assessment during admissions could help to address such issues.

iii. Attitude

It is important to treat people with dignity and respect. Compassionate care is essential to one's well-being. Service providers' behaviour should reflect positive attitudes towards people with disabilities.

It was stressed several times that people with disabilities want to receive the same level of care as everyone else. It is important to see an individual as a person first before their disabilities.

This referenced an example of a child with a disability who was not given a CT scan after a fall despite a clear indication of swelling on the forehead.

Participants said that there need to be a change in mindset when working with people with disabilities. Families feel they need to stay with their loved ones in order to be sure that they are safe during care delivery. People with intellectual disabilities are treated as children and presumed to have no capacity.

Probing for more information when providing care to people with intellectual disabilities would be helpful to understand their health conditions, as some might not have the vocabulary to explain how they feel. This was raised after a parent shared a story of their child who had a tomato stuck in their throat for days before they could cough it out.

iv. Need to Work Collaboratively

Participants stated over and over again that we need to work together to share information and knowledge so patients and families can be better supported. Families know how to best calm their child(ren) / family member(s) and can play a role in their care. It was suggested that information from partner organizations can be shared on screens in waiting rooms, for example, information on HRM infrastructure, or services provided by CNIB. It was also suggested that we need to showcase the services of patient representatives (staff who answer questions about care and experiences) and other health services available. It was encouraged that NSHA and IWK work together to bridge gaps between services and for employees to become aware of all services or locations outside their own.

***"There need to be more training and professional development for service providers, especially on various intellectual and physical disabilities"***

Summary of Areas of Improvement:

- Staff should have more training and professional development to learn about intellectual and physical disabilities that exist and proper use of language
- Give people with disabilities the same level of care as everyone else. See the patient as an individual first, before their disability
- IWK and NSHA need to work more collaboratively between departments and the community
- Cultural competence education should be extended to various diverse populations, not only for people with disabilities.

## *D. Evaluation summary*

Twenty-three out of 42 participants completed the event evaluation form. All participants who completed the form 'strongly agreed' or 'agreed' with statements including:

- *I was able to express my views freely*

- *I feel my views were heard*
- *I feel that the input provided through this conversation will be considered by the organizers*.

Some responses to the question – What was the best thing about this Accessibility Consultation Forum were*:*

- *having an opportunity to hear lived experiences and also connecting with decision-makers*
- *there is more than physical accessible concerns, that communication is also a barrier*
- *that people care*
- *knowing that someone is listening*.

Suggested improvements for future conversations were:

- *a room with better acoustics*
- *a follow-up day*
- *a visual presentation of what services are in place*.

Most people who completed the evaluation were women, of European descent, had completed a post-graduate training or degree, 55 to 70 years of age, and did not identify as having a disability.

## *E. Conclusion*

Accessible health care remains a pivotal part of achieving health for all. Throughout the conversation it was clear that a significant number of people with disabilities are not accessing care services because of barriers they encounter, including physical, language and attitudes of those who provide care. When asked how the challenges and barriers impact their health, it was clear that people experience increased stress levels, poor mental health, and a sense of desperation. People with disabilities frequent emergency departments because they have waited until their conditions worsen in fear of inaccessible services. Finances were also stated as the possible contributor to services excluding people with disabilities, therefore prioritizing the need for accessible services requires attention to reduce disparities. It was strongly mentioned that health care organizations should exemplify optimum standards for accessibility and reflect this in their accreditation.

## Members of the workgroup

Credit for the planning, implementation and compilation of this report goes to the workgroup that was put together by both the NSHA Central Zone and IWK's Diversity and Inclusion committees. Each member brought their professional expertise and thoughtful input to the fruition of this work. Though some of the members could not make meetings due to work commitment, their feedback contributed to the success of this work.

List of members:
Representatives from the IWK;

- Diversity & Inclusion (PH) – Tyro Setlhong, Children's Health; Rehabilitation Services – Nicole Works, Ambulatory Surgical Care – Shelley Saunders, Shared Clinic – Sharon Gavin Snyder, and Social Work – Dawn LeBlanc, Volunteer Services – Jim Nickle, Autism Research Centre – Isabel Smith, Spiritual Health – Rev. Elaine Walcott, Occupational Health – Pamela MacLean, Human Resource – Allison Praught, Redevelopment and Infrastructure – Ian Williams and Maintenance and Facilities Planning – Devin Peterson.

Representatives from NSHA Central:

- Public Engagement – Anna Jacobs, Diversity & Inclusion – Mohamed Yaffa, Mental Health – Jennifer MacLennan

Community Partners:

- Atlantic Provinces Special Education Authority (APSEA); Amy Parsons & Sheila Jamieson

## Appendix A

Participants for the People with Disabilities Community conversation

| Name | Organization |
|---|---|
| Barb Horner | Huntington's Disease Society |
| Laughie Rutt | Diversity and Inclusion, Halifax Regional Municipality |
| Jen Powley | Community Health Board member, accompanied by personal assistant |
| Crystal Tobin | Community Health Board member |
| Nancy Beaton | Canadian Paraplegic Association Nova Scotia (CPANS) |
| Amy Donnelly | Halifax Nova Scotia Down Syndrome Society (NSDSS) |
| Sara Abdo | Immigrant Services Association of Nova Scotia (ISANS) |
| Pam Gow Boyd | Canadian National Institute for the Blind, Halifax (CNIB) |
| Frank O'Sullivan | Society of Deaf and Hard of Hearing Nova Scotia (SDHHNS) |
| Nancy Walker | Autism Nova Scotia |
| Kristie Allister | Autism Nova Scotia |
| Betty MacDonald | Society of Deaf and Hard of Hearing Nova Scotia (SDHHNS) |
| James Hubley | Nova Scotia Health Authority, Human Resource |
| Jean Coleman | Nova Scotia Association of Community Living (NSACL) |
| Doriano Sablone | Nova Scotia Health Authority, Engineering |
| Darrell Robar | Canadian Paraplegic Association Nova Scotia (CPANS) |
| Vicki Harvey | Autism Nova Scotia |
| Mark Yeadon | Nova Scotia Health Authority, Engineering |
| Sherry Costa | Independent Living Nova Scotia (ILNS) |
| Joanne Comeau | Nova Scotia Health Authority, Neuro Spinal Cord Injury |
| Brian Tapper | Nova Scotia Health Authority, Rehabilitation Services |
| Margaret Angus | Nova Scotia Health Authority, Communications & Public Relation |
| Jenn MacLennan | Nova Scotia Health Authority, Mental Health |
| Robert MacKinley | Nova Scotia Health Authority, Emergency |
| Randi Munroe | Nova Scotia Health Authority, Rehabilitation Services |
| Mohammad Harb | Community member with an interpreter |
| Amy MacDonald | IWK Health Centre, Primary Health |
| Mohamed Yaffa | Nova Scotia Health Authority, Diversity and Inclusion |
| Pamela MacLean | IWK Health Centre, Occupational Health |
| Dawn LeBlanc | IWK Health Centre, Children's Health Social Work |
| Rev. Elaine Walcott | IWK Health Centre, Spiritual Health |
| Nicole Holland | Nova Scotia Health Authority, Interpretation Services |
| Anna Jacobs | Nova Scotia Health Authority, Public Engagement |

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| Kelsey Shea | Nova Scotia Health Authority, Emergency Halifax Infirmary |
| Tara Parsons | Canadian Paraplegic Association Nova Scotia (CPANS) |
| Tyro Setlhong | IWK Health Centre, Primary Health |
| Wendy McVeigh | Nova Scotia Health Authority, Continuing Care |
| Jo-Lynn Fenton | Autism Nova Scotia |
| Allison Praught | IWK Health Centre, Human Resource |