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# **The State of Health Care Accessibility for people impacted by FASD in Eastern Ontario as defined by the Accessibility for Ontarians with Disabilities Act**

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**FOR THE RURAL FASD SUPPORT NETWORK**



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**This study has been approved by the Community Research Ethics Office of Waterloo, ON. A copy of the approval can be requested by contacting the Rural FASD Support Network at [ruralfasd@gmail.com](mailto:ruralfasd@gmail.com).**

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## **I. Introduction**

Fetal Alcohol Spectrum Disorder (FASD) is a broad spectrum neurological disorder caused by prenatal alcohol exposure, and results in lifelong cognitive, developmental, physical, emotional, and social impairments (Cook, 2015). Individuals with an FASD diagnosis have an increased need for physical and mental healthcare, however often face barriers due to accessibility and stigma within healthcare and community settings (Dunbar, 2021). Individuals with an FASD diagnosis can live with impaired literacy, and unique social and emotional needs, creating additional need for support in healthcare access. In 2005, the province of Ontario introduced the Accessibility for Ontarians with Disabilities Act (AODA) to remove barriers for people with disabilities, and in 2016, the AODA integrated 5 accessibility standards to ensure that all Ontarians, including those with disabilities have equitable, and accessible support (AODA, 2016). This research will explore the experiences of 15 individuals, each identifying with one of the following three subcategories: individuals with an FASD diagnosis, parents/caregivers of an individual with an FASD diagnosis, and local health and mental health service providers, to understand the accessibility of the Ontario healthcare system for individuals with FASD living in rural Eastern Ontario. This report will focus on 3 of the 5 integrated standards of the AODA including (1) Information and Communications Standard, (2) Transportation Standard and (3) Design of Public Spaces Standard (Integrated Accessibility Standards [IAS], 2016) to assess the current accessibility and inform future standards for Ontarians with disabilities.

## **II. Background**

The Integrated Accessibility Standards under the Accessibility for Ontarians with Disabilities Act govern how organizations must meet specific standards to ensure their spaces and services are accessible to people with disabilities in Ontario (IAS, 2016). These standards can include things like wide sidewalks and doorways, offering alternatives to information sharing such as large print, or audio versions of text, and disability-informed service provision. In addition to the 5 standards included in the AODA 2016, additional standards for accessible healthcare and education are being developed. The unique strengths, needs and challenges of individuals with Fetal Alcohol Spectrum Disorder create increased barriers to healthcare access. While all individuals with an FASD diagnosis face significant cognitive impairment, the characteristics and behaviours vary greatly for each individual, and diverse social and environmental factors contribute to different social and health outcomes across the population (Flannigan, 2021). The social determinants of health, or the social, economic and environmental factors that contribute to health outcomes, negatively impact people of low socio-economic status, including people with disabilities (Friedman, 2020). People with a diagnosis of FASD are disproportionately impacted by mental health issues, substance use, involvement in the criminal justice system, poverty and unemployment, and without appropriate and accessible healthcare, are at a greater risk of negative social and health outcomes (Flannigan, 2021). People living in

rural settings in Ontario face barriers pertaining to transportation and availability of appropriate supports in their area (Robinson, 2021). This research aims to explore the experiences of healthcare access for individuals living with or impacted by FASD in rural eastern Ontario. It seeks to identify current facilitators and barriers to healthcare access, and recommendations for implementation of additional accessibility measures. The research will then explore the narratives of healthcare service providers in rural Eastern Ontario who have some experience supporting individuals with FASD in varying community settings. The interviews will seek to identify current accommodations provided to patients/clients with FASD, and additional measures that could support in providing the appropriate level of care and support required. Data collection will be focused on (3) of the (5) Integrated Accessibility Standards outlined in the Accessibility for Ontarians with Disabilities Act (2016) including; Information and Communications Standard, Design of Public Spaces Standard, and Transportation Standard to explore the current accessibility of healthcare through each lens.

### *1. Information and Communications*

The Information and Communications Standard of the AODA recognizes the need to create accessible means of collecting and sharing information for people with disabilities. These measures include things such as large print or braille for individuals with visual impairments, or audio/digital versions of text or reiteration of information in clear language for individuals who have difficulties with learning and literacy (IAS, 2016). Many individuals with an FASD diagnosis have severe impairments in executive functioning, including difficulties with planning and problem solving, and also experience difficulties with learning and memory (Mattson et al., 2019). Individuals with impairments in learning and executive function create a need for specialized support with information and communication sharing (Doyle et al., 2018). Decreased memory and learning pose a challenge when people with FASD are being given information about their physical and mental health. Appropriate accommodation to ensure information is being shared in an accessible manner, based on their individualized needs is often required. Impairments in executive functioning specify a need to support clients in the planning and facilitation of health and mental health related care plans.

### *2. Design of Public Spaces*

The design of Public Spaces standard of the AODA mandates that public spaces be designed in a way that is accessible for people with disabilities. This can include accessible parking, ramps and wide doorways, and accessible public outdoor spaces like picnic areas and beaches. (IAS, 2016). Individuals with an FASD diagnosis commonly identify with issues in sensory processing and adaptive functioning, including sensitivity to auditory and visual stimuli (Carr et al., 2010). These individuals experience difficulty in adaptive functioning including affect regulation, and experience higher rates of anxiety (Temple et al., 2019). Individuals with FASD might require additional accommodation when experiencing overcrowded environments, and may also require additional support with anxiety around healthcare access in order to

mitigate potential negative physiological and emotional responses related to these stimuli. Issues with adaptive functioning and affect regulation create difficulties in regulating the emotional responses related to sensory and emotional processing, and could result in potentially negative experiences in these settings.

### *3. Transportation*

The Transportation Standard outlined by the AODA orders transportation services to offer accessible ways for individuals with disabilities to commute. This can include things like ramps and guide bars on bus entrances and exits, accessible booking measures for specialized transit, audio and visual prompts for routes of transit, and the implementation of policies for equitable access to taxis for people with disabilities (IAS, 2016). Individuals living in rural settings have limited access to public transit, and often rely on taxis, which can be costly especially for individuals of low socioeconomic status, and specialized transit, to commute to and from healthcare appointments. Specialized transportation services such as paratransit require advance booking procedures which can be difficult to navigate for people with FASD given their difficulties in executive functioning and planning. People with neurodevelopmental disabilities, including FASD face systemic barriers to accessing traditional forms of transportation such as difficulty navigating transit systems and schedules, risk of harm due to vulnerability, and stigma and discrimination due to lack of training and knowledge possessed by transportation providers (Friedman & Rizzolo, 2016). The provision of accessible transportation support for individuals with FASD may help to facilitate healthcare access, particularly for those in rural settings where affordable public transit is unavailable.

Little research has been conducted on the individual experiences of individuals with FASD and healthcare accessibility, however research into caregiver's experience indicates that multiple systems levels barriers exist for individuals accessing services and support in the community (Petrenko et al., 2019). Barriers such as limited FASD-informed care in health and clinical settings, lack of availability of specialized services, barriers to diagnosis and limited resources, negatively impact people living with FASD (Petrenko et al., 2014). These systemic barriers contribute to the development of secondary conditions such as involvement in the criminal justice system, mental health problems, and substance use and addiction, placing a large emotional and financial burden on families and society (pg. 1498). Creating accessible health and mental health care for individuals with FASD can support in mitigating the effects of secondary conditions by directly linking individuals with care that meets their specific needs. Currently only three Canadian provinces have developed specific strategies for addressing the needs of individuals living with FASD including Alberta, Manitoba and the Yukon, while Ontario has implemented a budget to increase awareness and prevention of FASD, without a designated strategic plan (Burns et al., 2020). This research aims to provide evidence-based information from individuals directly impacted by FASD to support in developing a strategy to address the specific needs of individuals and families in Ontario who are impacted by FASD. By assessing the perceptions of accessibility of healthcare from individuals, families and caregivers,

and healthcare service providers, and how each group interprets accessibility, we can gain a comprehensive understanding of healthcare accessibility in rural eastern Ontario for individuals with FASD. From this comprehensive data, we can identify facilitators to equitable and accessible healthcare for individuals with FASD. Ensuring appropriate and accessible healthcare is needed to mitigate or prevent secondary conditions related to FASD, and will support the long-term management of FASD and its related conditions.

### **III. Methods and Ethical Considerations**

Research participants for this study include individuals residing in Rural Eastern Ontario who meet one or more of the following criteria (1) individuals living with an FASD diagnosis, (2) caregivers or service providers of an individual living with an FASD diagnosis, and (3) Healthcare providers inclusive of physical, mental and emotional health. Materials including a recruitment poster, and an email invitation for participation were disseminated across all contact networks of the Rural FASD Support Network, including email contacts, and the agency facebook page to scan for research participant interest. A second round of recruitment materials was sent to those who had not yet expressed interest in participation. Interested individuals were further assessed to ensure they met the inclusion criteria for participation. Special consideration was made for individuals who required accommodation for participation, to ensure the voices of people with lived experience were incorporated in the data. Audio versions of letters of information and consent were provided when required by participants, and ongoing conversations about consent were engaged throughout the research process to ensure ethical considerations were addressed. Individuals requiring consent from a guardian were considered and included in the recruitment process. Accommodations were made for individuals who required support from a caregiver to participate in the research, and additional consent forms were required by individuals providing support.

16 Semi-structured interviews were conducted both in-person and online to identify strengths in the current accessibility of healthcare for individuals with FASD, as well as explored potential areas of development to meet AODA accessibility standards. Five individuals had a diagnosis of FASD (3 male, 2 female), six individuals were caregivers of one or more individuals with FASD (2 male, 4 female) and 5 community and mental healthcare providers, with a range of experience supporting individuals with FASD (2 male, 3 female). It is noteworthy that while interviewing a wide breadth of healthcare service providers was intended, only healthcare providers offering community and mental health services were available to participate in an interview. Interviews conducted online were recorded on Zoom, and in-person interviews were audio recorded for further review and analysis. All individuals were asked the same series of questions, however language in the questions was changed to reflect the different positions of the subgroups in the research. By asking strengths-based questions, the researcher is able to identify facilitators to healthcare access, and evaluate recommendations for further advancement in accessibility procedures. Consideration of the need for consistency in the lives of people with FASD was taken. Upon request, interviews conducted with individuals living with FASD were

accompanied by a consistent care provider employed by Rural FASD Support Network, to mitigate negative consequences concerning lack of rapport between the researcher and research participants. Engaging in semi-structured interviews allows for all research participants to share individual subjective experiences and perceptions of accessibility in multiple systems. The integration of the experiences of individuals living with FASD as well as their caregivers and healthcare providers will provide a multi-level understanding of healthcare accessibility for individuals with FASD.

Recordings and transcriptions of the research interviews were thoroughly reviewed by the primary researcher, to uncover themes and patterns in the data. Data were initially analyzed based on themes that presented across all three subgroups of research participants. Data were then analyzed for themes that emerged within each individual subgroup. Seeking themes across and within the sub-groups allowed the researcher to identify common barriers and facilitators to healthcare accessibility across multiple systems levels including individual, family, community, and institutional.

Individuals who are impacted by FASD were included in each step of the research process. Consultation with caregivers of individuals with FASD informed the ethical guidelines of the research project, the development of the research questions and scope, the composition of the interview questions, and the review of the final themes. This allowed the research project to meet the unique needs of individuals with FASD, and ensure that research best practice was exercised throughout the process. Individuals were given the opportunity to review the final written report, and provide feedback which was considered during the editing and revision process.

#### **IV. Findings**

Sixteen individuals were interviewed to understand the experience of healthcare accessibility through semi-structured interviews with individuals in the FASD community in Rural Eastern Ontario. 7 participants identify as male, 9 participants identify as female, and all individuals who were interviewed are over the age of 16. Two research participants identify as Indigenous/First Nations/Inuit/Métis, while 13 individuals are Caucasian. The following section will begin by outlining three distinct themes that emerged during interviews with all three subgroups, followed by a description of emerging themes within two or less individual subgroups to support a multi-level understanding of the accessibility of healthcare for individuals with FASD in Rural Eastern Ontario. The section will conclude with suggestions for recommendations based on the three standards of accessibility in healthcare settings.

##### Findings across all sub-groups

###### *1. Limited Transitional-Aged and Adult Support*



Many individuals with FASD face challenges in the accessibility of services and support to meet their healthcare needs during the transition from the children's system, into the adult system. Much of the interview data placed an emphasis on the limited mental health support during the transition and into adulthood. While the majority of participants felt that their experience with the children's mental healthcare system was generally accessible, with some difficulty with lack of FASD-informed support, accessing services during youth and adulthood is more challenging. One individual with FASD spoke about their experience transitioning into the adult mental health care system: *"you're in crisis now, and you have to wait how long before you can get anybody to talk to...and by that time, it's all over."* P101. A caregiver spoke about their experience supporting their daughter who has complex mental and emotional health needs: *"She was receiving services from children's mental health. [Child's Name] didn't receive services over the summer, and when she returned she had two sessions, and they closed the file because she timed out, and there was no transition." .... "Things had to get bad enough that we ended up going to hospital for emergency consultation. From there, we will have 5-6 sessions with a social worker from the hospital and children's mental health, but then the file will be closed." .....* *"With [Child's Name's] history, and FASD and mental health in particular, you can figure that there will be lifelong support needed in some fashion."* P002. One caregiver discussed their son's experience as an adult accessing mental health support: *"They hadn't heard from our son for about 6 months, he didn't answer things, and at 23, I wasn't involved in that way, so I wasn't getting these messages. So the parameters are that if you don't hear from someone for 6-months, you close the file. Then you have to go through the process of applying again... Those kinds of rules within the system don't work for individuals with an FASD diagnosis."* Another caregiver discussed their concern with being an aging parent, implications of this when they are no longer able to provide the necessary support when their children transition into adulthood: *"Now the thing that we are considering now because of age, being 61, is how is this going to look in five years?"* P002. One individual with FASD spoke about his need for support to and from appointments prior to having his driver's license: *"If I didn't drive myself, I would have to rely on someone. I don't feel comfortable taking public transportation."* P104. One healthcare worker spoke about the difficulty in navigating systems, particularly for individuals with FASD who are entering adulthood: *"A lot of agencies will use the phrase "we can't put in more effort than the client" and with a lot of individuals who are at a transitional age, service providers need to understand that it is unlikely that the child will ever put in as much effort as the providers - so you have to put in more effort."* - P203. The limited support for individuals with FASD during the transition from the children's system, into the adult system presented as a common theme across interviews with individuals with FASD and caregivers of adolescents and young adults. This gap in service can increase the likelihood that individuals without regular caregiver support into adulthood will be at a greater risk of experiencing secondary conditions relating to their FASD.

## 2. Siloed Services creating barriers to system navigation

Due to the prevalence of comorbid conditions associated with FASD, individuals with this diagnosis are often required to access varying levels of the healthcare system, for example primary care, mental health and psychiatric care, specialists, occupational and physical therapy and dental clinics more frequently. The disbursement of services across a wide geographical range, coupled with a lack of communication between care providers emerged as an obvious theme throughout interviews with all three subgroups. The lack of consistency and communication across services lead to difficulty in obtaining diagnosis, difficulty in navigating mental health systems, and difficulty in managing consultations with multiple specialists to address the varying health concerns experienced by individuals with FASD. Many individuals with FASD spoke about their experience with navigating appointments with multiple care providers. One spoke about the importance of having a rapport with his doctor, and his increased anxiety when meeting new doctors, and seeing new specialists: *“If it’s my doctor, I’m comfortable, if it’s a [fill in] doctor, then I feel uncomfortable.”* P103. Another spoke about the lack of communication between care providers: *“Trust me, I’ve talked to specialists that don’t talk to other specialists, and, oh it’s a mess”* P104. One participant spoke about their experience with navigating the siloed mental healthcare systems: *“It’s overwhelming, it’s like why can’t one program do it all, instead of me meeting with a whole bunch of people that are trying to do the same thing but they are all doing different steps.”* P105. Caregivers discussed their experience of navigating through multiple systems of care that are disconnected from one another. One caregiver spoke about their process of navigating the healthcare system with their children who have varying health challenges: *“I was never referred further. It’s been confusing, I have these kids with all of these challenges, and I’m going to doctors, and I have all of these organizations involved and I’m saying - “What do I do? Where do I go” Just tell me what I need to do and I will ask and I will push” - and they kind of look at you like.. ‘I don’t know where to send you’”* P002. All healthcare providers acknowledged the siloed nature of the healthcare system, and discussed a need for education on the community supports that are available to help both families impacted by FASD and care providers with system navigation and advocacy support.

***“Think how overwhelming it is for a person with FASD to have to travel to 12 agencies. To be able to go to one facility that they are familiar with, they see people they know, that they are comfortable with, they can trust.... That would be the ideal” P001***

### *3. Lack of FASD Informed Supports*

The most distinct theme that emerged from each individual interview surrounded a lack of FASD-Informed support in the majority of healthcare settings. Individuals who were interviewed were able to identify two major FASD-Informed clinics that offer diagnosis and FASD care and support, with one located in Kingston, Ontario, approximately 100 km from the

research participant pool, and one located in Ottawa, Ontario, approximately 80 km from the research participant pool. A small number of participants were able to identify individual local healthcare providers such as pediatricians, or mental health care practitioners who offer the necessary accommodations for themselves or their children, however individuals with FASD are frequently required to attend various health related appointments, and often find it difficult to find someone who is FASD-informed. Individuals with FASD felt healthcare providers lacked the necessary understanding of FASD to provide the client-centered accommodations and service. One individual discussed the lack of FASD-informed care providers in the healthcare system, as well as his own lack of knowledge on FASD and its impact on his journey through diagnosis: *“I have been misdiagnosed many times, with many different things in the mental healthcare system. I’ve been put on drugs that don’t work, drugs that get me sick, and getting the initial diagnosis of FASD, I was kind of like ‘oh it’s just another one, they’re going to pump me full of drugs’.. And then they told me ‘well, there’s nothing we can do.’ I didn’t put any real faith in the diagnosis, but I went home and I researched it myself, and it kind of just made my life make sense”* - P104. Caregivers also spoke to the difficulty of navigating the healthcare system when care providers are not informed. One caregiver spoke to their experience seeking care providers for their children with FASD: *“Finding an FASD-informed doctor or therapist is challenging. They will claim to know about FASD, but it’s clear they don’t once you get into the thick of it”* - P005. Some healthcare providers expressed a limited understanding of FASD, while some served the FASD community directly, and had an extensive understanding of the impact of FASD, and the client-centered approach that is required with the demographic. One healthcare provider discussed the difficulty with ensuring adequate training to serve the diverse needs of individuals diagnosed with FASD: *“Service providers want to do well, but caseloads are high. There’s a certain amount of time allotted to training, and there’s still a lot to learn”* - P203. A lack of FASD-informed healthcare can create gaps in service that may lead to negative health outcomes and a greater likelihood of developing secondary conditions for individuals with FASD. Most research participants were cognisant of the limited resources available for care providers, and recognized the breadth of information about FASD and limited time and resources that leads to the gaps in accessible service.

***“Well the whole medical establishment is not understanding FASD to begin with. It’s only in the last 10 years that medical professionals have started to take it seriously, but there’s still a lot of people who aren’t trained yet. We need them trained in understanding and recognizing how to work with people with FASD.” P104***

#### Findings within sub-groups

### **V. Individuals with FASD & Caregivers**

## 1. Limited autonomy in healthcare

Individuals with FASD, and caregivers identified limited autonomy in healthcare settings for individuals with FASD. Data collected from transitional aged youth with FASD and caregivers identified a strong dependence on caregiver support for all aspects of their healthcare, including scheduling, planning, transportation, communication, mental and emotional support, decision making and system navigation. Individuals without access to a personal vehicle were unable to identify any accessible or affordable options to travel to their health related appointments. Some research participants identified positive experiences with individual pediatricians, or mental healthcare professionals in terms of information sharing. Most participants identified a need for caregivers or other support to translate information in plain language, and offer different methods of information delivery following healthcare appointments to ensure patients with FASD are informed about their health. All individuals with FASD and caregivers of individuals with FASD identified a difficulty comprehending and remembering the information being shared with them about their, or their children's health, and identified a need for varying levels of accommodation to be implemented in this area to best support individuals with FASD to act with autonomy in health related decisions. One youth with FASD discussed their experience at appointments when trying to understand the information being provided by their care providers: *"Well, normally mom usually translates that stuff for me, because I don't really speak doctor care speech, I speak mechanic speech."* P103. One individual with FASD who doesn't have caregiver support, but sometimes leans on friends and others for support with medical appointments discussed their experience when gathering information about their health, and their experience when advocating for themselves: *"Doctors are in such a hurry that they can't take the time, you have to be there to ask the pertinent questions, otherwise they just give you a reader's digest version and you're left wondering. I take a proactive approach to my health and ask the questions... sometimes doctors don't like me."* 104. Individuals with FASD and their caregivers shared that when attending appointments, it is unlikely that care providers will speak directly to the patient, unless a strong rapport is established over time. One caregiver discussed their varying experiences with this: *"We're lucky with our developmental pediatrician, she is very good, and she will make sure she is speaking to them so she is very good... now, going to our general practitioner, is a different story... they're dysregulated [with all of the stimuli] .. our general practitioners struggle to get to their level."* P005. One caregiver spoke about their experience following medical appointments with their loved one: *"I have seen her leave meetings, and medical appointments or otherwise, and cry, because she didn't understand what they said. She would often leave or consent to a procedure or otherwise and say 'I felt pressured' or 'I felt like I couldn't say no' or that the language they use doesn't take FASD into account."* - P002. Two individuals with FASD identified that disclosing their diagnosis to certain care providers was further detrimental to their autonomy. One individual shared their experience when disclosing their FASD diagnosis: *"If they find out I have FASD, they don't treat me the same, they would rather talk to my husband.....I'm perfectly capable of having them explain*

*everything to me.” - P101. Another participant shared their experience with a lack of autonomy, a need for advocacy: “I had to go out and learn everything I could about FASD and my health so that doctors would take me seriously.” - P105. A caregiver participant shared a story about their son’s journey through complex health related concerns: “[Child’s Name] has had a few surgeries now, so it was involving urology, so, in terms of information they give you that one page text paper that explains what it is going to be like to go through surgery, how you you are going to feel, how you might feel afterwards, and with his sensory profile, yeah..he really felt it..... He certainly wasn’t prepared for what the surgery was going to be like, and what it was going to be like after.” The caregiver then described the experience on the day of the procedure: “The surgeon comes in, rattles off his script, [Child’s name] didn’t understand any of it.” The caregiver then discussed the impact the lack of information accommodation has on their son’s developmental health: “He would certainly describe it as a traumatic event, which is why he doesn’t discuss this with anybody....When I asked him if he would be willing to participate in the research and share about about his experience with medical professionals, that’s where his mind goes. Those extreme anxiety levels, the upset stomach he talks about, it’s all based on that... he thinks every time he goes to a Doctor’s office at [organization name] now, that the same type of thing is going to happen to him, because he didn’t understand it then, and most of the time he doesn’t understand that now, so he’s concerned he will be met with an awful surprise again.”*

P001. Healthcare providers who provide FASD-informed community support described creative and proactive strategies for engaging individuals with FASD in their own healthcare, which will be discussed in the recommendations section of the report. While patients have the right to act with autonomy in their own healthcare, data collected demonstrates that further accommodation is required when serving individuals with FASD, to ensure these individuals are being appropriately and adequately informed about their health and are given the ability to make informed health related decisions. The lack of accommodation for information and communications from care providers can have detrimental impact on individuals without caregiver support or community advocacy.

***“People deserve to have an informed choice, and if they make the choice that it’s too much, and they don’t want to pursue it... but the choice should be there’s, and you can’t make that choice unless it’s an informed choice. We always work from the standpoint of ‘You gotta tell them like it is’ and go from there.” P-001***

## *2. Inaccessible spaces*

Data collected from both Individuals with FASD and their caregivers highlighted the limited accessibility of contemporary healthcare spaces for individuals with FASD. Individuals with FASD often have challenges in affect regulation and sensory processing and have difficulty with anxiety regulation in environments that have increased visual and auditory stimuli. Data collected from individuals with FASD and their caregivers indicates that attending appointments

in busy hospitals, and spending time in crowded waitrooms results in increased levels of anxiety, and dysregulation during medical appointments. When asked about their experience with busy wait-rooms, one participant with FASD explained: *“From my point of view, I’d say it needlessly ups my stress level.”* All participants with FASD explained the feelings of discomfort and anxiety caused by the level of stimulation in overcrowded medical facilities. One participant explained what they would do when faced with a busy waiting area: *“If I have to wait a long time, one, I walk out the door; two, my mother [makes me stay]”* - P103. Caregivers discussed feelings of stigma, for both themselves and their loved ones when attending medical appointments, and advocated for special consideration to be made to accommodate individuals with FASD. One caregiver shared their frequent experience when supporting their child in a dysregulated and overstimulated state: *“You are in the room, and you know people are bothered by your child - so you need something separate...definitely.”* P003. Another caregiver spoke about their adult son, who also struggles with spending time in overcrowded healthcare settings and how the stigma impacts his ability to access healthcare comfortably: *“The stigma weighs heavy on him around FASD, mental health, the crisis he has got himself through... so a lot of it depends on how open minded he is...what he has already lived through influences how he experiences these appointments now”* P004. While accessibility considerations are implemented for individuals with physical accessibility challenges in healthcare settings, the necessary accommodations for individuals with FASD are often not available. One individual with FASD described her experience of anxiety when attending appointments for their mental health: *“There should be stuff accessible to these people that can calm them down and get them in the right mindset before they talk about the hard things they might need to talk about.”* P106. Research participants within all three subcategories spoke about some suitable accommodations that have been successful in mitigating the negative outcomes related to dysregulation, stigma and developmental trauma in healthcare settings. These accommodations will be elaborated on in the recommendations section of the report. Consideration for the needs of individuals with sensory processing and affect regulation as a result of their disability should be considered in healthcare settings to ensure all individuals are able to attend their health related appointments, and discuss information related to their health in a comfortable and regulated state.

***“The waiting room is the most difficult. The less time we have to spend in the waiting room, the better the outcome will be.” P005***

## **VI. Recommendations**

### *1. Information and Communications*

Individuals with FASD who participated in the research commonly reported that healthcare providers rarely share health related information directly with them, rather their caregivers are most commonly the individuals receiving the information and offering support to rephrase in plain language following their appointments. Caregivers expressed that they are responsible to retain and rephrase all health related information using language and

communication styles that individuals with FASD can understand. Healthcare providers identified that their intention is always to speak directly to the patient and some healthcare providers were able to offer different strategies they use to ensure the patient/client is understanding the information being provided to them at their medical appointments. All individuals interviewed offered similar recommendations pertaining to the way healthcare providers can offer health related information in a way that is accessible for individuals with FASD.

***“I don’t understand it, but my mom [simplifies] it for me..It’s usually my mom that reminds me of the information” P104***

**a. Client-centered information and communication**

Individuals with FASD, caregivers and healthcare providers were able to provide suggestions for how healthcare providers can offer accessible information and communication, particularly for individuals with FASD. Offering client-centered accommodations is the most highly recommended accommodation offered throughout the research. Offering information in written-form using plain language and concrete explanations is an effective way to help individuals with FASD understand their health related information, given the prevalence of receptive and expressive language challenges and difficulties with learning and memory. Having information in written form offers individuals the opportunity to review and further explore the information about their health following their appointments. Offering visual aids such as social stories and videos to help individuals with FASD understand certain procedures is also highly recommended. Another way to best support individuals with FASD to act with autonomy and best retain the information discussed at health related appointments is to allow for audio recording, so individuals are able to listen to the information, and share it with their caregivers following their appointments. Healthcare providers acknowledge the varying needs of individuals with FASD, and encourage patients, clients and caregivers to ask for particular accommodations when there is a need identified.

***“Basically they would have to do it a bunch of times to remember, it has to be spoken a bunch of times for me to remember what it was.” P103***

***“Even something as simple as the doctor slowly reading the paper on video, and then sending them the link... that would definitely be better than where it’s at right now.” - P001***

**b. FASD-Informed systems navigator in large healthcare settings**

As discussed earlier in the findings section, there is a general gap in knowledge and awareness of FASD and the specific needs of this population among healthcare providers. As such, healthcare providers fail to provide the necessary accommodations to ensure healthcare information is being shared in a manner that is accessible for individuals with FASD. Individuals

who participated in the research acknowledge the complexity and variability of need for individuals with FASD, and recommend the implementation of an FASD-Informed systems navigator in hospitals and large-scale healthcare settings to help bridge the gap between healthcare providers and individuals with FASD accessing healthcare. The increased demand on caregivers to both offer social and emotional support to their loved ones, while simultaneously retaining and rephrasing information to their children places pressure on the caregivers to perform multiple conflicting roles. The implementation of a systems navigator could offer note-taking services, translation/rephrasing services, and advocate on behalf of the patient, to healthcare providers, to offer accessible information and communication to ensure caregivers have the capacity to support their loved ones through the dysregulation many experience when attending appointments.

**“If there was a hospital ambassador that created a video that could explain what the experience is like, that he could get his head wrapped around it.”**

Other recommendations provided include ensuring healthcare providers are asking patients and clients about any accommodations they might require, and empowering clients to advocate for their needs in medical settings. Healthcare providers who provide direct community support to individuals with FASD and their families encourage healthcare providers to support patients and clients with inputting scheduled appointment reminders in their phone, offering reminder phone calls, texts or emails based on client’s preferred mode of communication, and offering additional appointment reminders.

***“They don’t necessarily recognize how important it is to call back. Providers need to understand they might need to try again, and that would come with knowledge of FASD.”***

***P004***

***“They are at the age where they are allowed to make decisions.. The youngest at age 13 would have went ‘ya ok’ to anything.. Like stopping mental health services. Whereas the oldest becomes overwhelmed and needs my support.” P002***

## ***2. Design of Public Spaces***

As discussed in the earlier section of the report, spaces such as medical offices and hospitals often generate increased anxiety and dysregulation for individuals with FASD. The main barrier to accessible healthcare identified within the design of public spaces standard surrounded the busy waiting areas and long wait times, which both decrease the accessibility of healthcare settings for individuals with FASD. All subgroups discussed the need for accommodations when individuals with FASD attend these settings for appointments and two strong themes emerged as recommendations to support accessibility.

### **a. Quiet sensory-conscious space**



All individuals who were interviewed including individuals with FASD, caregivers and healthcare providers identified offering a separate, sensory conscious waiting space for individuals with FASD and others who have challenges with sensory processing and affect regulation. The recommendations for this space include calm colours, fidget toys and other activities such as colouring, soft music and videos. This space would offer individuals with FASD the opportunity to remain regulated while awaiting their appointments, ensuring they can engage with care providers and act with autonomy in their healthcare.

***“A more quiet space would be better.” “Like have a smaller like, waiting room or something, that is not as big and crowded” P103***

***“I found the one thing that was good, I had to sit there and wait for a really long time, so they got my brother and I iPads so we could sit there and play the whole time. Doing that and distracting my mind before I had to go in and talk about touchy topics. It helped” P105***

#### **b. Notification Service to limit wait times**

A second recommendation provided by all three subgroups of participants included a virtual notification service. Spending long amounts of time in busy waiting spaces decreases the likelihood that individuals with FASD will attend their appointments in a regulated state. Offering email, or text notifications to patients, following check-in, when their appointment time is approaching would give individuals the opportunity to spend their time waiting outside of the busy waiting space, and return when their appointment time arrives.

Other recommendations include offering more sensory friendly waiting areas inclusive of movies, toys and other opportunities to ensure individuals with FASD can remain engaged and regulated while they await their appointments.

***“[mental health clinician] does all their sessions through Zoom, and every once in a while he will say he wants to physically go see [mental health clinician], and she’s got this great sensory room, it’s what she specializes in. It’s comparable beyond belief... She leaves a window between appointments, he never waits” - P001***

### **3. Transportation**

Individuals who participated in the research identified barriers to transportation, predominantly around availability of affordable and FASD-informed services, and the proximity of available FASD-informed support. Almost all individuals with FASD who were interviewed depend on their caregivers for transportation to and from medical appointments. All caregivers identified being the regular provider of transportation to appointments, even those with adult children with FASD. Healthcare providers commonly suggested that a taxi could be arranged for individuals who were having difficulty accessing transportation for their appointments, however this is something that is available upon request. Caregivers and individuals with FASD identified

that taxis are not always accessible for individuals with FASD given their complex support needs, especially during high stress events such as medical appointments. Several recommendations were made that could support the development of more accessible transportation, particularly for those living in rural settings, such as the individuals in this research pool.

**a. Offer Virtual Appointments**

All individuals who were interviewed identified that attending their appointments through a virtual platform when possible was preferred to help mitigate both the transportation barrier, as well as the increased levels of dysregulation experienced by individuals with FASD when attending healthcare appointments. Healthcare workers identified offering virtual appointments when optional as a feasible way to ensure transportation barriers are avoided in most cases. Offering appointments through a virtual platform such as phone consultation or video chat supports individuals with FASD on varying levels. Caregivers identified the time to travel to medical appointments often means they and their children are required to take a day off of school and work, further adding to the anxiety and dysregulation experienced by individuals with FASD when attending medical appointments. Attending appointments virtually allows the client/patient to remain in a space that is comfortable and familiar, supporting the accessibility of the appointment beyond simply removing the transportation barrier.

**b. FASD-Informed transportation service**

Some individuals who were interviewed identified that a volunteer driving service could support people in attending their appointments and help to avoid the barrier of transportation. All individuals who made this recommendation also suggest that an FASD-Informed driver or support person would be required given the nature of the service. Due to the increased levels of anxiety and dysregulation experienced by individuals with FASD when attending medical appointments, the driver of this service would need to have an understanding of FASD and its characteristics in order to provide the level of support that might be required by some individuals using the service.

Other recommendations included a mobile health service for individuals who are living in rural/remote areas who may not have access to reliable transportation, and ensuring that individuals with FASD and their families are informed of the available transportation support that is offered by individual organizations.

**“Realistically they would have to move to town if they needed accessible transportation”....”We are in the middle of nowhere - it suits well with FASD” P002**

## **VII. Discussion**

This study explores the lived experiences of individuals with FASD, their caregivers, and healthcare professionals to understand the current accessibility of healthcare settings in Eastern Ontario, and what necessary accessibility measures should be considered when developing The Healthcare Standard of the Accessibility for Ontarians with Disabilities Act. The report offers

accessibility recommendations from individuals with lived experience that should be implemented by individual healthcare providers, organizations, and the wider healthcare system to support equitable and accessible healthcare for individuals with FASD. The unique strengths and challenges of individuals with FASD create barriers when accessing conventional healthcare settings, however, measures can be taken that consider the strengths of these individuals, ensuring they can act with autonomy in their healthcare. Data indicates that 4% of the North American population is living with FASD, and it is suspected that this is an underrepresentation, given the invisibility of the disorder, and varying social and environmental circumstances of individuals at-risk of FASD (Flannigan et al., 2022, McLachlan et al., 2020, Cook et al., 2015). While the current study indicates high levels of support and advocacy from caregivers of children with FASD, special consideration should be made when exploring the needs of adolescents, transition-aged youth, and adults with FASD. Given the difficulties of daily living experienced by individuals with FASD including school disruption, unemployment, independent living needs, housing insecurity, legal involvement, and alcohol and substance misuse, it is imperative that individuals with FASD are able to access services that employ their strengths, to reduce their likelihood of experiencing negative outcomes (McLachlan et al., 2020, Flannigan et al., 2022, Harding et al., 2019). Having access to reliable and accessible transportation, client-centered communications and information sharing, and FASD conscious spaces within the healthcare system can support individuals with FASD to maintain their overall health, and mitigate the impacts of secondary conditions in adolescence and adulthood.

Data reported that in most cases, individuals with FASD rely on their caregivers to access their healthcare related appointments. Given the rural setting of the research pool, all individuals have to travel far distances for their medical appointments, and require access to a personal or family vehicle for a reliable means of transportation. The Accessibility for Ontarians with Disabilities Act mandates accessible transportation be available for individuals with disabilities (IAS, 2016). The conventional modes of transportation offered to individuals with disabilities such as public transportation, and accessible driving services often lack the level of support required for individuals with FASD to use these options. Secondly, due to the complex nature of the FASD and its diagnostic measures, individuals with FASD sometimes do not qualify for certain social benefits towards transportation support. As individuals living in rural settings transition into adulthood, access to reliable, accessible and equitable transportation options will be imperative in maintaining their physical, mental and emotional health. Eliminating stigma within the community, and enhancing the knowledge of FASD will help to foster services that could effectively offer accessible and equitable transportation. While public transportation offers accessibility for individuals with mobility challenges, and hearing and vision impairments, individuals with FASD experience challenges resulting from their disability that are not considered on conventional public transportation. Individuals with FASD have challenges with executive functioning, including with planning, memory (Mattson et al., 2019, McLachlan et al., 2020) Difficulties in executive functioning make planning and scheduling their transportation challenging. Individuals also face challenges with sensory processing and adaptive functioning

including increased sensitivity to light, and sound, and difficulty with emotional regulation, making crowded public transportation highly inaccessible for this population. Accessibility considerations for individuals with FASD on public transportation would include considerations for planning and navigating schedules, and FASD-informed, sensory conscious transportation options. Consideration should be made when assessing eligibility criteria for social funding and support for transportation costs, as individuals with FASD will often experience challenges with employment, and income security, limiting the affordability of independent transportation options. While many of the research participants identified that caregivers are responsible for transportation support, transition-aged youth and their caregivers were unable to identify any reliable and accessible transportation options in their area. As youth with FASD transition into adulthood, accessible transportation will be imperative for individuals with FASD who are living independently in rural settings. Without adequate healthcare, individuals with FASD can be at a greater risk of experiencing secondary symptoms such as challenges with addiction, unemployment, poverty and suicidal ideation.

In most cases, caregivers and individuals with FASD described a strong dependence on caregiver support for information and communications being shared at medical appointments. Caregivers adopt the responsibility to provide information to their children in plain language, and offer alternative methods of information sharing so their children can be informed about their health. The Information and Communications standard of the AODA identifies that individuals have the right to access information in a manner that is accessible to their needs (IAS, 2016). The patient bill of rights indicates that patients have the right to be fully informed about their health status, be informed of treatment options, and actively participate in decision making related to their health (C.4). As children with FASD transition into adolescence and adulthood and are exercising more independence in their healthcare, a greater need for accommodations around information and communication sharing will be required from healthcare providers. Individuals with FASD identified that healthcare providers should take special consideration to speak slowly and in plain language, offer multiple reiterations of information, offer opportunities for audio recording or take-home videos, and offering information in written format would effectively allow individuals to exercise their rights outlined the Patient Bill of Rights, and act with more autonomy in their healthcare. As individuals with FASD transition into adulthood, their challenges with receptive and expressive language, memory and planning can make it difficult to act with independence in current conventional healthcare settings. Ensuring that individuals are adequately informed and engaged in their healthcare is essential in mitigating the potential for the development of secondary conditions associated with FASD, and will ensure they are able to maintain their mental, physical and emotional health over the life-course. As more healthcare providers become informed about FASD, and adequate support is implemented in large-scale healthcare settings, individuals with FASD will have the opportunity to work within a system, offering adequate support and considerations for their individual needs.

The way in which conventional healthcare settings are designed poses challenges to accessibility for individuals with FASD. Data reported that individuals with FASD experience

increased levels of dysregulation and anxiety when attending crowded and overstimulating healthcare settings. Caregivers identified increased pressure to offer emotional and psychological support to their children, while simultaneously engaging in their health related matters. Under the Design of Public Spaces Standard of the AODA, individuals have the right to accessible spaces, regardless of their disability (IAS, 2016). Because individuals with FASD experience challenges with sensory processing and affect regulation, contemporary waiting spaces generate increased anxiety levels and decreased ability to regulate physical and emotional responses to overstimulation in busy areas. As discussed in the previous section, the implementation of an FASD-Informed systems navigator would serve to eliminate some of the strain experienced by caregivers of individuals with FASD during healthcare appointments. While the dysregulation experienced by individuals with FASD can be mitigated by caregivers, as individuals with FASD move towards adulthood, increased awareness of their needs in the design of healthcare settings will require consideration. The main identified barrier to accessibility of healthcare spaces is around the busy waiting areas, and individuals with FASD, their caregivers, and healthcare providers all identified a need for a more sensory conscious waiting space for individuals with FASD, to ensure they are able to maintain emotional regulation while they wait for their appointments. Attending their appointments in a more regulated state will allow individuals with FASD to actively engage and participate in their appointments, and offer the opportunity for these individuals to act with more autonomy in their healthcare, especially when limited caregiver support is available to individuals with FASD in adulthood.

## **VIII. Conclusion**

Individuals with FASD have unique strengths that can be exercised to ensure they can act with autonomy in their own healthcare. Special consideration for the unique challenges of individuals with FASD is imperative to ensure these strengths can be fostered in healthcare settings. Consideration for the specific transportation needs of individuals with FASD living in rural and remote areas is imperative to ensure individuals without access to reliable transportation can maintain their health related appointments. Acknowledgement and understanding of the expressive and receptive language challenges, and implementation of client-centered accommodations is required for information and communication, especially as individuals with FASD transition into adulthood. Consideration for the sensory needs of individuals with FASD in healthcare settings can help to mitigate some of the emotional and physical dysregulation experienced by individuals with FASD, and will support the development of more sensory conscious spaces. Increased awareness and understanding of FASD by healthcare providers and staff is imperative to develop a system of care that meets the unique needs of individuals with FASD. As a Healthcare Standard is developed within the AODA, consideration for the needs of individuals with FASD will ensure that this population can maintain their health, and decrease their risk of secondary associated symptoms of FASD, which can create large levels of financial strain on the greater healthcare system. Implementation of the

recommendations identified in this data will support individuals with FASD to exercise their strengths, and their right to autonomy in their healthcare over the lifecourse.

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