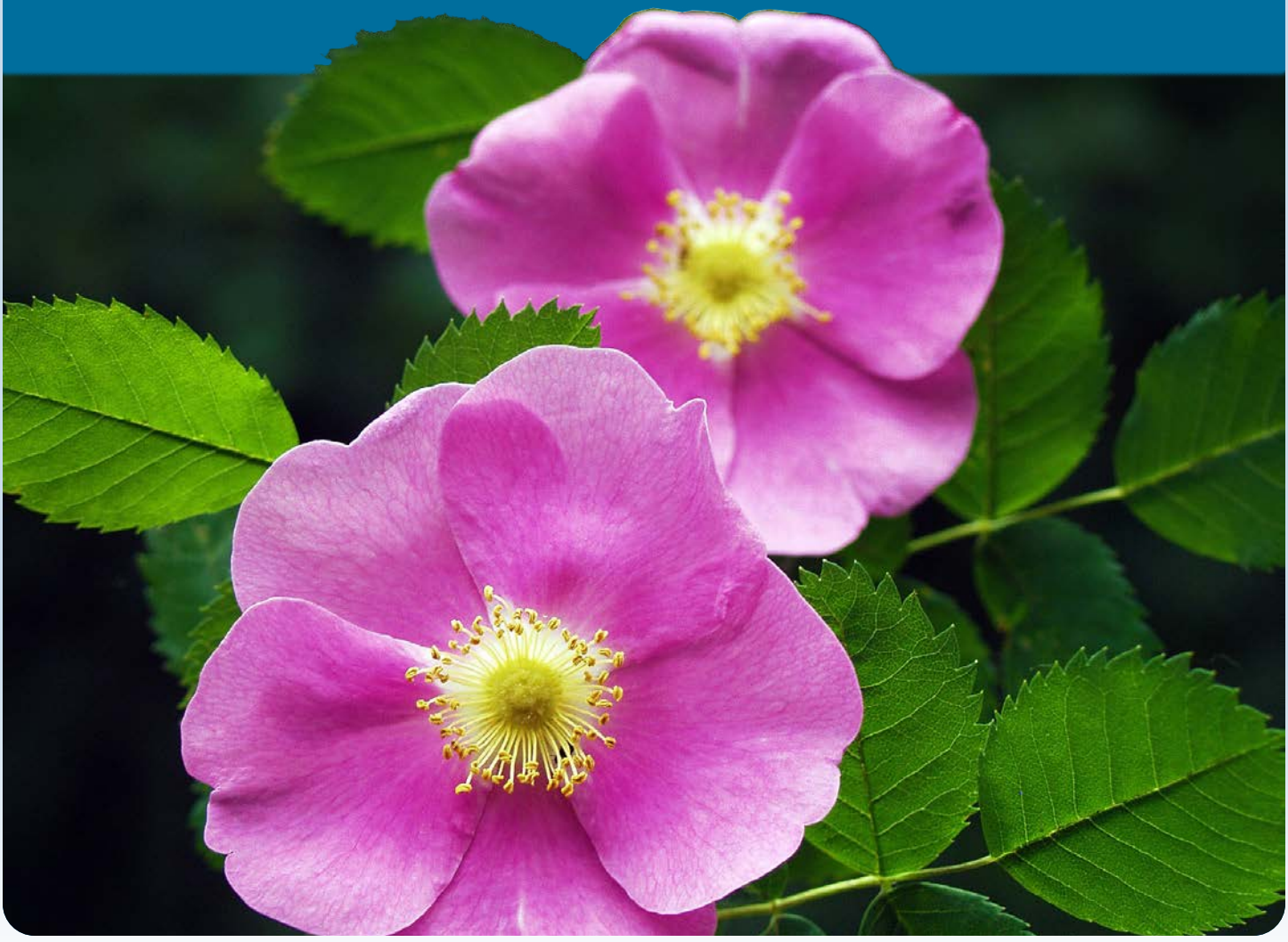
# The FASD Patient Journey



The Alberta FASD Cross Ministry Committee

2020

## Contact

For more information, please contact

Randal Bell
Provincial Planning and Capacity Management
Provincial Addiction and Mental Health
Randal.Bell@ahs.ca

The FASD Patient Journey report only includes the voices and perspectives of those persons with FASD that were in a position of supported availability. Many of the persons with FASD interviewed herein, had their names put forward by various support persons or support services. Indeed there exists a swath of persons with FASD, that are not connected to an FASD support person or service and connecting to them for the purposes of setting up an interview was not possible for that very reason. While this report identifies unmet needs of persons with FASD, it must be acknowledged there are many whose needs are higher and whose voices could not be included in this report.

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- Carmen Longworth, Alberta, Gaming Liquor and Cannabis
- Doug Vincent, Alberta Health Services, Community, Seniors and Addiction & Mental Health
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- Jodie Bakker, Justice and Solicitor General, Strategic and Business Services
- Mary Ann Ho, Community and Social Services, FASD Initiatives, Disability Services
- Michael Stansberry, Justice and Solicitor General, Young Offender Branch
- Rhonda Stangeland, Alberta Education, School and Community Supports
- Richard Dumas, Indigenous Relations, Employment Partnerships Advisor
- Robert Rock, Advanced Education, Post-Secondary Programs
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The FASD Patient Journey Project wouldn't have been possible without the voices of the 127 people who opened their hearts and shared their incredibly important stories with us. Thank you all so very much.

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# Executive Summary

In September 2018, the Alberta FASD Cross Ministry Committee initiated an FASD Patient Journey Project to examine the current state of FASD services and supports from the perspective of persons with FASD, their caregivers and their service providers. After 120 interviews in 34 communities across Alberta, the project team has captured not only their perspectives on service delivery but their frustrations, ideas, hopes and dreams as well.

These perspectives are captured throughout the report in the form of direct quotations. It is important to include these quotations as they provide a raw firsthand account of the challenges and complexities of FASD. They illustrate the daily struggles of FASD service providers, of caregivers and of persons living with FASD.

After capturing and analyzing these perspectives, the project team has produced recommendations they believe will address the many concerns of the persons interviewed. The recommendations for FASD service enhancement focus on these five key areas. They are as follows:

1. **FASD Assessment and Diagnosis**
   a. Increase Access to FASD Assessments and Re-assessments
2. **Community-Based Services & Supports**
   a. Review FASD Access to Multidisciplinary Teams
   b. Review Funding and Access Criteria to PDD Program
   c. Review the Funding and Accessibility of FSCD and PDD Supports
   d. Assess FASD Needs for Affordable Housing, Supportive Living Resources and Transition Beds
   e. Review the Funding and Accessibility of FASD Network Support Workers
3. **Addiction and Mental Health Supports**
   a. Review of Addiction & Mental Health Access for Persons with FASD
   b. An FASD Awareness Strategy for Addiction and Mental Health
   c. Expanding FASD-Friendly Treatment Options
4. **Community Awareness**
   a. An FASD Awareness Strategy in Alberta's Public Services and Health Services
   b. A Provincial FASD Stigma-Reduction Campaign
   c. A Corrections FASD Project
5. **FASD Care Planning**
   a. Sharing the Lethbridge Collaborative Model
   b. Develop Transition Planning Pathways

These fourteen recommendations are a direct response to the feedback we received from persons with FASD, their caregivers and their service providers. These FASD recommendations are described in greater detail in Section 6 of this report.

# Section 1: Project Background

In 2002, a group of representatives from government ministries, provincial authorities and community-based organizations came together to develop a coordinated approach to addressing FASD in Alberta. The approach was to consider FASD across the lifespan and would include a continuum of services that was “respectful of individual, family and community diversity” (“Alberta Cross Ministry Committee”, 2019).

In 2007, the Government of Alberta led a cross-ministry collaboration to develop Alberta’s 10-Year Strategic Plan to address FASD in Alberta. The strategic plan would provide a framework for how FASD services were developed and delivered in Alberta for the next 10 years.

In 2017, with the Alberta 10-Year Strategic Plan and the Year 7 Evaluation still fresh in their minds, the FASD Cross Ministry Committee endorsed the concept of a project that would capture the perspective of persons with FASD, their caregivers and their service providers.

In 2018, the FASD Patient Journey Project proposal was presented to the FASD Cross Ministry Committee and was well received. The FASD Patient Journey Project interviews commenced in September 2018.

# Section 2: Project Objective

The FASD Patient Journey Project sought to understand the patient and client journey from the perspective of persons with FASD, their caregivers and their service providers. By listening to their stories, the project team was able to identify what they felt was working, what was not working and what, in their opinion, was missing in services and supports available to persons with FASD and their families.

Further to identifying gaps in service delivery, the project team was able to capture what a person with FASD felt would enhance service delivery. The project team was also able to capture what caregivers and service providers felt would enhance service delivery. In this way the project team was able to capture a 360 degree picture of how services could be improved to meet the needs of persons with FASD in a way that would work for them, their caregivers and the families.

## 2.1: Project Description

The FASD Patient Journey Project consisted of 120 mixed (qualitative and quantitative) interviews in 33 communities across Alberta (see communities listed below). Listening to persons with FASD and hearing about their many challenges and experiences was an effective way to learn about FASD and available FASD supports, but we went a step further, choosing to interview caregivers and service providers too.

Persons with FASD face a number of challenges with day-to-day life and are not always articulate in advocating for their needs. For this reason, caregivers need to be very active in the care planning process, often finding themselves in an advocacy role to access appropriate services and supports. Needless to say they are a vital source of information in trying to capture the patient journey of persons with FASD. Likewise, service providers play a very active role in the care planning and service coordination of persons with FASD. Whether it's limited staff or limited resources, service providers also face a number of challenges in trying to get the unique needs of their clientele met. An FASD patient journey would not be complete without capturing their perspective as well.

The interviews were somewhat informal but followed a consistent template and question sequence. The informal nature of the interviews allowed the participant to share his or her "story" at a pace they were comfortable with.

Interviews were conducted in settings that afforded appropriate comfort and privacy to the participant. Further, participants were encouraged to have a support person present and in most cases they did. Following the interview, there was a "check-in" to ensure any needs for debrief or further support were addressed. In all 120 interviews the participants declined further support following the interview and indicated it was a positive experience. In fact many participants expressed feelings of catharsis, and "it felt good to be heard" was a common sentiment.

The project interviewed 3 different cohorts using 3 different interview templates. The cohorts and interview elements are described below:

1. Convenience sample of 46 FASD Service providers:
   Interviews consisting of qualitative and quantitative questions from the following domains:
   a. FASD Education & Experience
   b. FASD Assessment & Diagnosis
   c. Community-Based Services & Supports
   d. FASD Care Planning
   e. Addiction & Mental Health Services
   f. Community Awareness
   g. Barriers and Challenges
   h. Opportunities for Service Enhancement

2. Convenience sample of 37 FASD Caregivers:
   Interviews consisting of qualitative and quantitative questions from the following domains:
   a. FASD Assessment & Diagnosis
   b. Community-Based Services & Supports
   c. Addiction & Mental Health Services
   d. Health Services & Supports
   e. Community Awareness
   f. FASD Care Planning
   g. Barriers and Challenges
   h. Opportunities for Service Enhancement

3. Convenience sample of 37 Persons with FASD aged 18–55:
   Interviews consisting of qualitative and quantitative questions from the following domains:
   a. FASD Assessment & Diagnosis
   b. Community-Based Services & Supports
   c. Addiction & Mental Health Services
   d. Health Services & Supports
   e. Community Awareness
   f. FASD Care planning
   g. Barriers and Challenges
   h. Opportunities for Service Enhancement

## 2.2: Interview Locations

Interview locations were predominantly identified via FASD Network offices throughout the province. However, a number of caregivers and service providers had heard about the project by word of mouth and contacted the project team expressing their interest in being interviewed.

Interviews were conducted in the following cities, towns and communities:

Airdrie
Athabasca
Bonneville
Calgary
Camrose
Cold Lake
Disbury
Edmonton
Edson
Fairview
Fort McMurray
Gift Lake
Grande Prairie
Grimshaw
High Level
High River
Hinton
Kehewin Cree Nation
Lacombe
Lethbridge
Medicine Hat
Millet
Okotoks
Red Deer
Rocky Mountain House
Slave Lake
St. Paul
Strathmore
Sunchild First Nation
Turner Valley
Wainwright
Westlock
Wetaskawin

# Section 3: Perspectives – FASD Service Providers

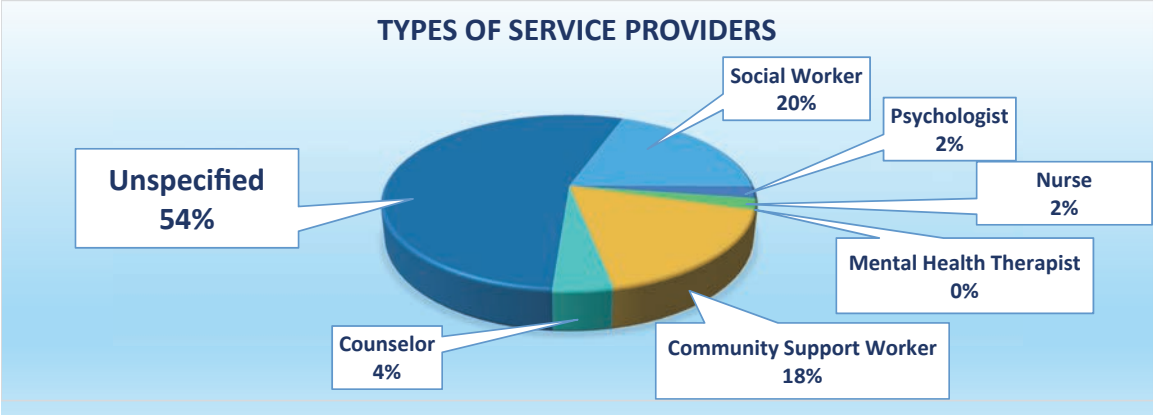
Many of the service providers interviewed for the FASD Patient Journey Project were keyworkers from the regional FASD Networks. However, there were a number of instances in which the keyworker was able to set up service provider interviews in the community-based services that their clients accessed. In some cases we interviewed a mentor who provided a few hours of weekly support, other times it was the director of a day program operating with a clubhouse model. The depth of the service provider data pool ensures a number of different perspectives in terms of what is working, what is not working and what is missing in available FASD services, and it gives us many different perspectives in terms of how services could be improved.

## 3.1: FASD Education & Experience

### What type of FASD Service provider are you?

See chart 3.1.1: When asked what type of background the service providers had in terms of education and experience, the vast majority fell under the category of ”Unspecified.” “Unspecified” meant they had a mixed variety of previous education and experience that did not fit in one of the identified categories. In fact, the project team was struck by how many of the service providers had multiple careers prior to working in FASD support services.

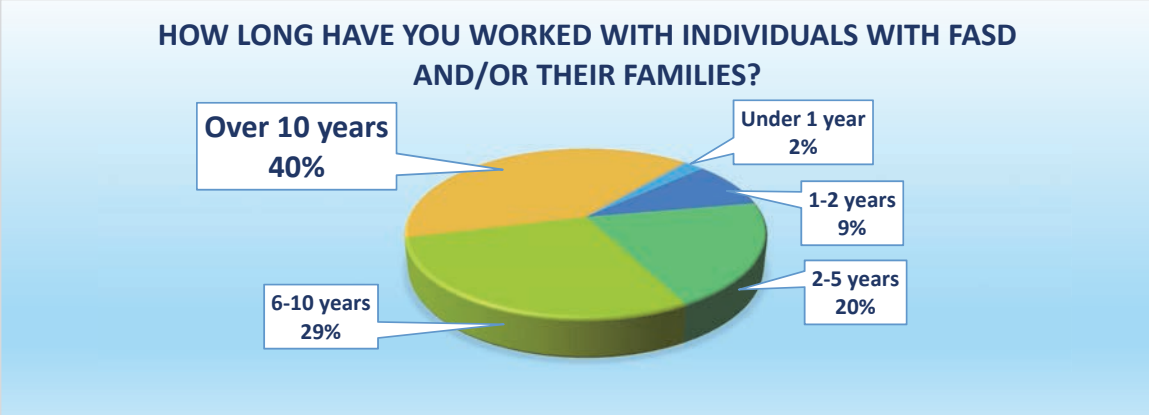
**CHART 3.1.1**



## How long have you worked with individuals with FASD and/or their families?

See chart 3.1.2: It would appear the vast majority of those who had chosen to work in an FASD support service had done so for over 6 years, with many working over 10 years (69%).

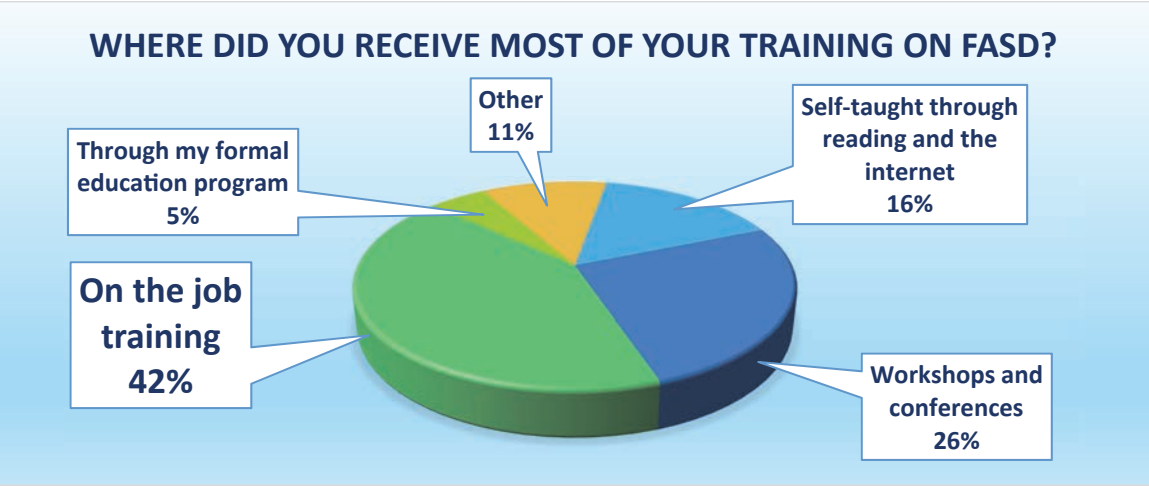
### CHART 3.1.2




## Where did you receive most of your training on FASD?

See chart 3.1.3: It was clear the majority of the FASD service providers relied on on-the-job training for the bulk of their FASD training (42%), with some having access to a formal n-house professional development plan (5%). Workshops and conferences also make up a significant portion of FASD-specific training (26%).

### CHART 3.1.3



## What specialized training have you had?

When asked about specialized FASD training, 65% of the service providers indicated that they had attended one or more workshops, seminars or conferences. However, the workshops and seminars varied and tended to include more general topics such as Ability in Me (AIM), Trauma Informed Care, Motivational Interviewing, Applied Suicide Intervention Skills Training (ASIST) and Harm Reduction. The workshops more specific to FASD tended to include Parent and Child Assistance Program (PCAP), Alberta Health Services (AHS), Renfrew and Pebbles.. A few of the service providers had attended FASD conferences in Alberta, in British Columbia and one service provider had attended an International conference.

Many of the service providers (30%) indicated that they received in-house FASD-specific training modules such as FASD 101. The FASD 101 training modules seemed to be quite well known in some regions but not so much in others.

28% of the service providers indicated they were connected to organizations that provided occasional continuing education opportunities, in one form or another.

Four of the service providers reported that they had completed FASD assessment training at an organization specializing in FASD assessment.

## How can training be improved?

There was variety in how service providers responded to the question of how FASD training could be improved but most stayed true to the central theme that more training was needed. In fact, 74% of the service provider responses indicated more FASD training was needed, in some way, shape or form.

26% of the service provider responses indicated that a standardized or province-wide FASD training platform was needed. Service providers described a need for train the trainer packages, FASD certification courses, minimum standard courses, an FASD training manual and centralized training.

*"There's a huge lack of training for new staff. There needs a provincial standardized training package that is delivered in-person; similar to PCAP (Parent-Child Assistance Program) core training."*

– Service provider, Hinton, AB

*"More funding for more trainers, which equals more access. There's nothing comprehensive…or centralized training. [FASD service provider] has more training than [FASD service provider]…through their hospital resources. An education training nucleus would be helpful."*

– Service provider, Calgary, AB

24% of the service providers indicated they'd like to see more funding for and access to continuing education and training opportunities.

*"It would be helpful if we had a bigger training budget and flexible training because FASD clients are always changing, always different."*

– Service provider, Athabasca, AB

*"I would like to see more FASD staff taking training and having access to more training that was affordable. Maybe an Alberta FASD training Manual and training like PCAP does."*

– Service provider, Grande Prairie, AB

17% of the service providers, indicated they would like to see FASD training more accessible to and accessed by the wider community, including community agencies, healthcare, education, justice system, etc.

*"If you are going into justice, corrections, addictions etc. you need to know about FASD. People need to be able to identify FASD and differentiate other related conditions."*

– Service provider, Westlock, AB

*"Everyone who is working with people need to have thorough training regarding this disability…including trauma and attachment. People have to move beyond books and academic knowledge. They need to understand the barriers of an invisible disability…as well as brain functioning. If you don't have training… despite your qualifications, you won't be helpful to this population."*

– Service provider, High River, AB

15% of the service providers felt FASD training needed to move away from "one-size-fits all" approaches, and consider more person-focused interventions with tailored strategies, as no two FASD clients were the same.

*"The training needs to emphasize that FASD is a spectrum and that no two clients will be the same. It needs to emphasize individual plans; and individualized interventions."*

– Service provider, Lethbridge, AB

*"(Training) needs to support individual person…focus on what works for each person depending on need. Need for relationship development…find out strategies for each individual that works. Most existing training focuses on the younger regarding homework and school focus…there's a lot less on adult focus and teaching focus."*

– Service provider, Calgary, AB

Finally 13% of the service providers indicated that FASD training was an immediate need to orientate staff that are new to working with FASD populations.

*"Maybe there should be an FASD orientation training package. More updated info on FASD."*

– Service provider, Hinton, AB

*"Training needs to be taken as soon as possible when working with FASD so they understand the population… the challenges."*

– Service provider, Lethbridge, AB

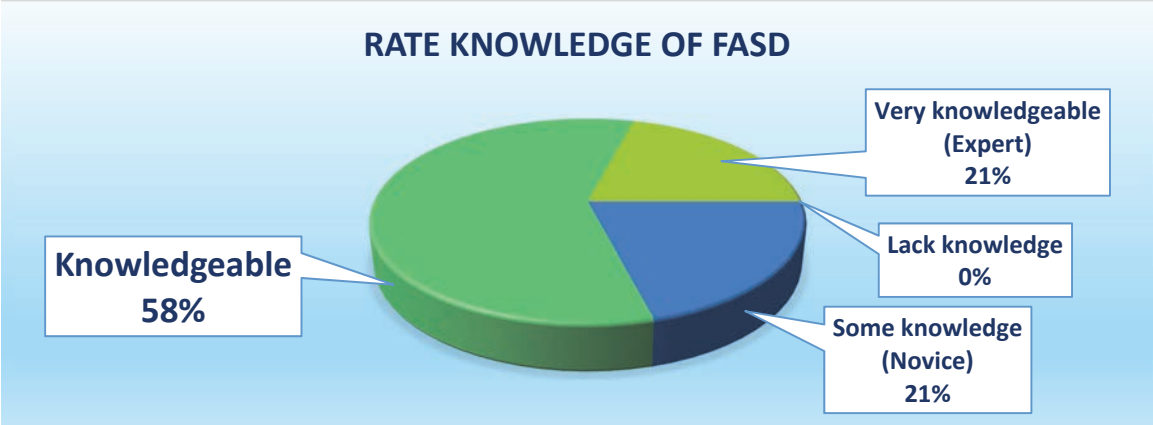
*"New people to the field should get FASD 101…what it is, foundations etc. Direct service staff need tools to be able to work with complex populations…toolkits, strategies, resources…staff need creative ideas to pass along to clients."*

– Service provider, Lethbridge, AB

### How would you rate your knowledge of FASD between 1 and 4?

See chart 3.1.4: It was clear the majority of the FASD service providers (58%) felt comfortable saying they were "knowledgeable" about FASD, with some even saying they were "Very knowledgeable" (21%). With that said, a smaller section of the cohort (21%) felt they would benefit from greater knowledge through further FASD education and training.

**CHART 3.1.4**




## 3.2: FASD Assessment & Diagnosis

Have you found that it is helpful to the family when the child has a formal diagnosis of FASD, as opposed to not having a diagnosis? Why or why not?

When the service providers were asked if having an FASD diagnosis was helpful to the family, 87% of the service providers indicated it was. The majority of the service providers (61%) indicated that it was essential to the caregivers as it gave them a basis for understanding their family member, in terms of challenges and behaviours.

*"Yes because the diagnosis comes with a strategy for caring for the individual. It helps the child and caregivers understand needs and they can be addressed sooner. There is a huge difference in the quality of life between someone who was diagnosed early in life and someone who was diagnosed later…they get that help and support earlier."*

– Service provider, Medicine Hat, AB

*"Yes. It answers so many unanswered questions. A lot of families get the diagnosis of foster kids later in life and say "had I known I would have done things a lot differently…instead of tough love."*

– Service provider, Westlock, AB

*"Yes. Parents understand their children a lot better and how to respond to their needs. I hear parents say "I finally understand my child now."*

– Service provider, Fairview, AB

A further 57% of the service providers indicated the diagnosis was essential in ensuring the families got the services and supports they needed.

*"I work with adults but they have kids… some with FASD. When they have a formal diagnosis the parent gets more supports and services. All the sudden they get educational supports…also they get parenting support and parenting strategies. They get FSCD (Family Supports for Children with Disabilities)… money and support for things like extra tutors and education supports. Parents think they are bad parents with bad kids… then they get the diagnosis and they begin to understand."*

– Service provider, Calgary, AB

*"Absolutely…the child will get the services they need early. This means they will get educational supports early too. We have clients who have gave on to post-secondary. Those who are adults and get an assessment have already experienced a lifetime of trauma and in many ways the damage is done. This makes it that much harder to learn new things and adapt. It helps the family understand and they can adapt and change in a way that's more responsive to the disability."*

– Service provider, High Level, AB

Finally, 22% of the service providers indicated that getting the diagnosis was important in terms of the family member's education, and the much needed educational supports.

*"Yes. Because we have the ability to get children credit disability which adds $200 to the tax credit and FSCD (Family Support for Children with Disability). It also gives you a better footing to work with the school and get needed supports. FASD is a brain-based disability."*

– Service provider, Grande Prairie, AB

*"Yes. With diagnosis they get services. Otherwise it's an invisible disability. With diagnosis comes more education, understanding and compassion. Without it comes more stigma, behavioural issues etc. With parenting…there is a real shift in approaches after assessment and diagnosis…an understanding of how the child's brain works."*

– Service provider, Calgary, AB

# 3.3: Community Services & Supports

## What programs and services have helped your clients with FASD in the past?

See chart 3.3.1: The service providers interviewed came from a number of different FASD-serving streams. Some of these service providers worked more with younger persons with FASD while others focused more on adults with FASD. When we look at the chart below it's clear that service providers make use of all available resources, programs and services when it comes to their clients with FASD, and they do so fairly consistently.

### CHART 3.3.1

## What service and program has been most helpful to the individuals/families that you worked with and why?

When asked which service or program was the most helpful to their clients 9% of the service providers indicated that all services are important and all are unique to the individual.

*"All these programs are extremely important…"*

– Service provider, Lethbridge, AB

*"No one individualized…there is no one-size-fits-all, it really depends on the person and the family. People can come into multiple systems and need to access many services."*

– Service provider, Lethbridge, AB

Many of the service providers felt strongly that income support was the most important service. 31% of the service providers felt income support and supplements provided through AISH (Assured Income for the Severely Handicapped), Alberta Supports or Alberta Works Centres were the most helpful.

*"AISH, you can't achieve anything without an income. A lot of clients have mental health issues and can't hold down a job."*

– Service provider, Hinton, AB

*"AISH…the quality of life increases dramatically when they have a steady income."*

– Service provider, Medicine Hat, AB

27% of the service providers indicated that access to community-based support programs was what made the biggest difference for their clients. These community programs included health-based services, addiction-based services, mental health-based services, justice-based services, rehabilitation-based services, housing-based services, education-based services and employment-based services.

*"The community support programs are the most helpful because they are the day-to-day supports keeping them out of hospitals and out of jail."*

– Service provider, Edmonton, AB

*"Community supports like [Justice service provider] are a really big support to my clients."*

– Service provider, Edmonton, AB

*"A lot of our clients have mental health issues and a lot of trauma. [Family Service provider] and [Homeless service provider] are very important and very helpful because housing and inner city resources are crucial."*

– Service provider, Edmonton, AB

20% of the service providers indicated that the FASD Network is what was most helpful to their clients.

*"…FASD Network helps families access assessments which is necessary to access other supports."*

– Service provider, Edmonton, AB

*"The FASD Network is probably most helpful as they know how best to help this population."*

– Service provider, Lethbridge, AB

*"The FASD Network is probably the most helpful. Because we will actually drive out to the Indigenous communities and pick them up."*

– Service provider, High Level, AB

16% of the service providers indicated that health services and other community-based health services were an important service to clients with FASD.

*"It varies from client to client. But health services are probably accessed most often; as is social assistance."*

– Service provider, Hinton, AB

*"Primary Care Network is a good partner with us in terms of trying to engage our clients in a longer term care relationship."*

– Service provider, Athabasca, AB

## How could services be improved?

When service providers were asked how available services could be improved, the responses fell in one or more of the following categories; increasing knowledge and training in working with individuals with FASD, reducing wait times for services, increasing supports available, increasing service accessibility and improving continuity of care.

38% of the service providers indicated staff needed increased FASD knowledge and more importantly, training on how to work with individuals with FASD. Specifically, service providers indicated that increased FASD knowledge and training was needed in the income support services (18%), policing and judicial support services (17%), mental health services (15%), healthcare (10%), addiction services (9%), employment services (7%), community-based support services (6%), housing services (4%) , education services (4%), child and family services (3%) and finally, 10% of the service providers indicated it is needed in all areas.

*"Mental health isn't very helpful. They lack expertise in FASD. CBT (Cognitive Behavioural Therapy) and traditional counselling will not work with FASD. They also rely too much on medication which rarely makes a difference and if it does they quite often forget to take them, or they lose them or they sell them. Their intervention should consider all elements of the patient."*

– Service provider, Athabasca, AB

*"There needs to be a lot more education and awareness for all professionals. I was at a doctor's appointment with a parent explaining her child had FASD…the doctor asked, "Can he talk? Like… will he understand me?"*

– Service provider, Grande Prairie, AB

*"Court and probation…they need a better understanding of FASD. They don't seem to understand that persons with FASD don't understand behaviour and consequences. I had a client with FASD who broke into someone's house to make something to eat. Police came and he kicked a police officer and was arrested. He ended up in Peace River Correctional. He had Down Syndrome also. He was moved to protective custody but he was still there for 4 months."*

– Service provider, Grande Prairie, AB

23% of the service providers indicated that services could be improved by increasing staff, services and supports. Specifically, they indicated a need to increase staff, services and supports in recreation, education and employment services, assessments for day-to-day supports, income support services and housing, financial management support (guardian/trustee etc.), Addiction and Mental Health support with staff trained in FASD, judicial support services, specialized outreach services, day-to-day community supports, and finally, rural-based support services.

*"We need a lot more access to affordable housing with staff that understand FASD clientele and their needs. A lot of services ban FASD clients when they don't understand FASD clientele."*

– Service provider, Lethbridge, AB

*"We need a lot more frontline staff at [FASD service provider] so I guess if we had more funding. We have huge caseloads and a waitlist to access assessments. So a lot of people are not getting the level of care and support they need."*

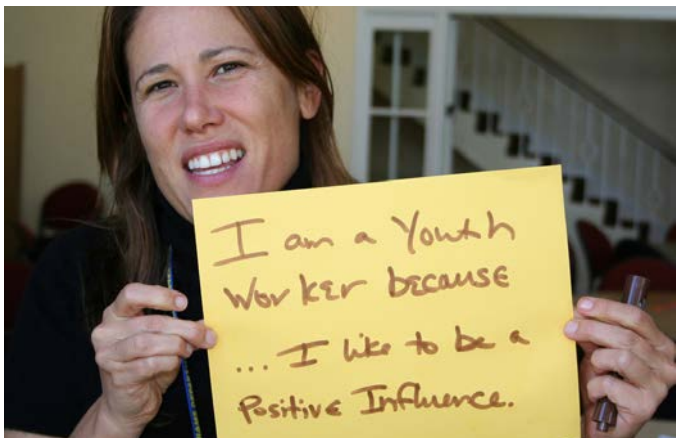
– Service provider, High Level, AB

*"Funding is inadequate for the population we are dealing with. We are only scratching the surface of the need; we need staff to do outreach."*

– Service provider, Medicine Hat, AB

*"A lot of the FASD clients I have need 24 hour support but the supports available can only provide about 10 hours a week and the people that show up for the 10 hours are not trained in FASD support. Other times they can't identify anyone to put the support in."*

– Service provider, Edmonton, AB



20% of the service providers indicated that supports could be improved with easier access. Specifically they mentioned easier access to assessments for FASD services and supports, easier access to housing, easier access to Addiction and Mental Health services, easier access to legal help, easier access to income support services, easier access to recreation, easier access to education and employment services and by expanding services in community agencies that provide FASD support.

*"We need a lot more housing and even shelters for men. There are no shelters here so we have had to send men to Edmonton on the bus so they can access shelters."*

– Service provider, Hinton, AB

*"The hoops that people have to jump through to get government's supports are too many. I have seen a client with an AISH application and we knew he couldn't read. So there is a real need for a front line service that helps them navigate the system to get services. We also have clients who get AISH but don't know how to manage money… people and users take advantage of them. [Family service provider] provides this service but they're like us, they're working well beyond capacity."*

– Service provider, Lethbridge, AB

10% of the service providers suggested that services could be improved by reducing wait times. Specifically, reducing wait times for FASD assessments, for Addiction and Mental Health services (including addiction treatment), for healthcare and finally, legal services.

*"[Justice service provider] means waiting on hold anywhere from 2 to 4 hours. All these services could be improved with shorter waitlists. Especially addiction services and access to rehab."*

– Service provider, Athabasca, AB

*"Income support…baseline income needs drastic improvement. All of my clients complain about how they are treated by the staff at income support. They need to treat people with dignity and respect. I have a client with multiple mental health issues and a recent FASD diagnosis. It took almost 9 years to get her assessed in the meantime we had to work the system to get her income. She had very poor executive functioning and a mood disorder so could not hold down a job."*

– Service provider, Hinton, AB

9% of the service providers indicated services could be improved by providing greater continuity of care. Service providers specifically mentioned support persons to help a person with FASD navigate the transition out of healthcare, addictions, mental health and/or corrections.

*"Addictions needs to be more robust in transition planning. Our clients will come out of detox and be dropped right back in their same community without a localized plan. It is the same for people leaving corrections."*

– Service provider, Athabasca, AB

## Have you experienced wait-times for services for your clients with FASD, and if so how long were the wait-times for those services?

All of the service providers reported that their clients with FASD have experienced wait times for services ranging from weeks and months to years. The waitlists were typically to access other services such as FASD assessments, housing, income support, addiction detox centres, addiction treatment centres, mental health, healthcare and other community-based services.

24% of the service providers reported waitlists for FASD assessments. These assessments are one of the services that have the longest waitlists ranging from 8 months to upwards of 3 years. According to service providers, assessments are allocated according to available funding and when the funding runs out, no more assessments are available (i.e. one of the FASD Networks is funded for 20 assessments per calendar year). This means individuals on the waitlist must wait until the next year to be assessed.

*"There is only so much money for assessments in any given year, once the money is gone there are no more assessments. We had to wait a whole year for an assessment and had to fight for income support during that time."*

– Service provider, Hinton, AB

*"18–24 month waitlist for FASD assessment; the longer we wait the more they fall behind and the greater the risk they will fall through the cracks. Time is of the essence."*

– Service provider, Grande Prairie, AB

*"[Family service provider] presented a report in which she said they had 2–3 year waitlists…but they said other diagnosis clinics are as much as 8 years."*

– Service provider, Lethbridge, AB

*"Lots of Lethbridge area agencies are at capacity for assessment and diagnosis… some waitlists also…funding for FASD has not increased for 12 years."*

– Service provider, Lethbridge, AB

Other diagnostic assessments are needed to access specialized services and supports. Another 4% of the service providers indicated there were wait times for other assessments like IQ tests for Persons with Developmental Disabilities (PDD) or psychiatric capacity assessments. The overarching concern with these wait times is that individuals with FASD often need the diagnosis to receive funding and access to other services and supports.

*"We have wait times or barriers for capacity assessments. We need them for guardianship orders (OPG), public trustees, addiction treatment centres; they're usually done by psychiatrists."*

– Service provider, Edmonton, AB

17% of the service providers indicated there was a long wait for addiction treatment and another 5% highlighted the waitlists for accessing detox. Some of the service providers cited difficulties with continuity of care between detox and addiction treatment.

*"Treatment and detox can have a waitlist of weeks or months…patients with FASD don't always understand how waitlists work and they get frustrated saying, "If I can't go now then I won't go at all."*

– Service provider, Cold Lake, AB

*"There are long-wait times for addictions treatment and a lot of programs will not accept a person with FASD."*

– Service provider, Medicine Hat, AB

*"The real problem here is our client makes a decision to go to treatment or detox and by the time the bed opens up the client is no longer interested. It's a very small window…detox has the same problem."*

– Service provider, Calgary, AB

*"Addictions treatment…it's four sessions for assessment, then they will help you get into treatment. Then there is a waitlist of a couple months for the treatment centres. Then the programming and staff is not responsive to persons with FASD. Then there is no discharge planning."*

– Service provider, High Level, AB

*"Yes…the frustrating part is people are in-the-moment and resources can't generally handle that. Waitlist is big barrier to accessing help. Detox waiting is also tough due to impulsivity, decreased self-regulation and decreased ability to plan."*

– Service provider, High River, AB

13% of the service providers indicated that housing waitlists were long, making housing near impossible to access.

*"A lot of waitlists in housing; there is a waitlist for a housing worker then once you get a worker you get put on a waitlist. A lot of clients give up and try to find housing on their own."*

– Service provider, Lethbridge, AB

*"Housing…There is no affordable or subsidized housing for persons with disabilities like FASD."*

– Service provider, Grande Prairie, AB

*"Subsidized housing lists are 2 years long. You cannot offer meaningful support to people without a roof over their head."*

– Service provider, Hinton, AB

12% of the service providers indicated that accessing mental health services such as outpatient programing or counselling has long wait times.

*"Over a year waitlist to get into see mental health services…for outpatient or community mental health."*

– Service provider, Calgary, AB

Some service providers raised concerns about their clients being ineligible for Mental Health services and supports, while some raised concerns about the accepted model of therapy not being appropriate for a person with FASD.

*"Yes. There are waitlists for everything… mental health supports. I have had clients wait 2 months for a mental health assessment. That's if mental health will see them. Mental health uses CBT (Cognitive Behavioural Therapy) which isn't always effective with FASD clients. Dialectical Behaviour Therapy (DBT) is the preferred model of intervention with FASD clients. Art therapy also works well."*

– Service provider, Medicine Hat, AB

Service providers also raised concerns about the use of mental health walk-in sites and how a new worker is assigned to the person with FASD each visit, until a key worker can be assigned. Service providers mentioned trust is particularly important to persons with FASD and the walk-in model was not facilitating the level of trust needed for effective FASD client engagement.

*"There is always a waitlist to access mental health. They have a walk-in clinic but there is still a waitlist for a key worker which means you have to come back in a week to a whole new worker and a lot of clients just don't go back."*

– Service provider, High Level, AB

11% of the service providers indicated that funding sources such as AISH (Assured Income for the Severely Handicapped), PDD (Persons with Developmental Disabilities), and FSCD (Family Support for Children with Disabilities) were long processes and the wait was dependent on the FASD assessments.

*"A lot of waitlists for FASD assessment… like 8 months. Waitlists for AISH…the application, the interview then a 3-5 month wait for approval."*

– Service provider, Hinton, AB

*"AISH has a waitlist like 6 months to a year. AISH has a service that helps with impulse control by paying rent and phone bills directly…Big waitlist for low income housing."*

– Service provider, Edmonton, AB

## 3.4: FASD Care Planning

### How do you ensure the family is included in the planning of the services provided?

When service providers were asked how they ensured family was involved with the care plan, 98% of them indicated they utilized a client-centred approach. If the individual is an adult and wanted their family, caregiver or other supports involved and those supports were wanting to be involved, service providers would include them in service planning upon consent. In some cases the service providers included the family in the initial assessment as well as the care planning, going so far as to provide transportation and support.

*"Family is included at the beginning of the assessment. We provide transportation support to facilitate attendance and inclusion. We try to include them at every step of the plan."*

– Service provider, Athabasca, AB

*"We do goals setting exercises to identify what goals are and who needs to support those goals. This normally includes family supports."*

– Service provider, Grande Prairie, AB

*"We have a person-centred planning app that involves family members and other agencies. These plans are reviewed and updated yearly and are available online through a secure server. The client can add or change their own plan."*

– Service provider, Edmonton, AB

34% of the service providers also indicated that in some cases there is no family involvement due to a disconnection from the biological family, broken or estranged relationships with family or the family is coping with their own challenges and are unable to participate in care planning.

*"Some are in adoptive homes, some foster homes, some are independent. In these cases we have to mediate, as caregiver and client want different things. A lot of parents still have addiction issues or are homeless themselves and are not able to support their child's plan."*

– Service provider, Calgary, AB

*"A lot of clients are adults and have burned bridges with family. We try to update family if they are involved."*

– Service provider, Lethbridge, AB

*"If family is involved …we meet with them and find out issues, current resources. Many of the kids in this program do not have family involvement, so we work with the caseworker in lieu of family involvement."*

– Service provider, Lethbridge, AB

## How would you rate the strength of collaborative and coordinated planning with other agencies and services when working with individuals with FASD and their families (between 1 to 4)?

See chart 3.4.1: When asked about the strength of collaborative and coordinated planning, the majority of the service providers (47%) felt there was "some collaborative and coordinated practice" while 29% indicated it was "coordinated with a case manager" and 17% felt it was "fully coordinated and collaborative." Only 7% of the service providers felt there was a "lack of collaborative and coordinated practice."

### CHART 3.4.1

## What type of coordination, collaboration, case management and/or collaborative case conferencing do you and/or your colleagues use when working with individuals with FASD and their families? Why or why not

The majority of the service providers (98%) indicated that they support persons with FASD and their families through active case management, service coordination, inter-agency collaboration, case-conferencing, effective communication and utilizing assessments to inform a care plan.

82% of service providers indicated they support persons with FASD and their families through some form of collaborative case conferencing or inter-agency coordination.

*"We are PDD-funded so we would have a big meeting with PDD staff, [Mental health service provider], skills team, psychiatrist and [Family service provider]."*

– Service provider, Edmonton, AB

*"We have case management meetings that include all local services…these include families and any services engaged in the plan."*

– Service provider, Athabasca, AB

*"In crisis scenarios we would have a larger case conference in which all client support services are invited. Sometimes a second smaller conference for the client if it's too overwhelming for the client's cognitive functioning."*

– Service provider, Hinton, AB

*"[Family service provider] tends to be the one who brings people together… to talk about diagnosis and set up ongoing collaboration to be on the same page for the client and families."*

– Service provider, Calgary, AB

Of particular note was the finding that 15% of the service providers (from Lethbridge) that utilized collaborative case conferencing did so through a community collective called the Collective Wisdom.

*"We have a Collective Wisdom group which is comprised of representatives from a number of different community organizations. We have a release of information and a confidentiality agreement so we can discuss individual cases and we sometimes invite the crown or PDD or whoever if we think they can contribute to the care plan."*

– Service provider, Lethbridge, AB

*and collaborative…Collective Wisdom approach and model is a process that is once a month in which we present a case and other funded agencies and community services come in to support and advise. It can have up to 20 people…to listen and strategize plans. Beyond funded FASD agencies there are other agencies as well and a case management plan."*

– Service provider, Lethbridge, AB

*"Because the area is small…it is very close*

18% of service providers indicated they relied heavily on assessment-informed care planning, effective communication, information sharing and most of them expressed a need or desire to work more collaboratively with other community agencies.

*"We do needs assessment and identify different services to meet those needs."*

*– Service provider, Cold Lake, AB*

*"A lot of informal contact, via telephone. In-person chats etc."*

– Service provider, Fort McMurray, AB

*"There is a lot of communication and information sharing that occurs; a lot of referrals."*

– Service provider, Lethbridge, AB

## How is this helpful?

Almost all of the service providers that utilize collaborative case conferencing (or some form of it) saw value in it. Some of the service provider's emphasized collaborative case conferencing as a means of ensuring all the persons with FASD had their needs met and felt supported.

*"Resource and information sharing…it's a benefit to the client and the programs."*

– Service provider, Calgary, AB

*"It ensures the plan meets the individual's needs on a case by case basis."*

– Service provider, Hinton, AB

*"It is responsive to the client's needs."*

– Service provider, Fort McMurray, AB

Some service providers felt collaborative case conferencing was an effective way to ensure agencies didn't work in isolation or duplicate service delivery.

*"This ensures we are not overlapping or duplicating services."*

– Service provider, Athabasca, AB

*"Helps with families and individuals to have everyone there to resource. It also makes work flow easier to have a sounding board and not working in silos."*

– Service provider, High River, AB

*"Not working in silos…otherwise services could not work, they would be stretched too thin otherwise. Dealing with different ministries, philosophies, finding common ways of doing work. This has taken a lot of work…developing face to face working relationships."*

– Service provider, Lethbridge, AB

Other service providers indicated that collaborative case conferencing was an effective means of keeping people accountable to their care plan commitments.

*"These case conferences keep the providers and the supports they provide accountable."*

– Service provider, Lethbridge, AB

*"(Collaborative case conferencing) helps keep track of multiple services."*

– Service provider, Calgary, AB

Finally some service providers felt collaborative case conferencing was an effective means of communication and information sharing.

*"It helps everybody stay in the loop; connected."*

– Service provider, High Level, AB

*"There is a lot of information sharing that occurs."*

– Service provider, Edmonton, AB

## How can this be improved?

In terms of improvement, all service providers had suggestions to improve the current collaborative case conferencing and the coordination of community-based services.

50% of service provider responses highlighted the need for community case conferencing to include more healthcare professionals and or more community-based services as appropriate.

*"An improvement would be more collaboration in hospitals and healthcare… more prevention."*

– Service provider, Lethbridge, AB

*"I would like to see the [FASD service provider] and supports take more of a leadership role in case management. If we can't get a doctor to a meeting, we can bring a report from the case management process back to the doctor."*

– Service provider, Grande Prairie, AB

*"There definitely needs to be more collaboration between agencies and supports. I would like to see one organization take the lead and organize an outreach team of all agencies so we can work together."*

– Service provider, Medicine Hat, AB

*"Larger systems could be supportive more…like [Health service provider]… maybe having less restrictions and more collaboration with non-profits. More support for front-line workers."*

– Service provider, Calgary, AB

28% of the service providers suggested more FASD education, training and awareness was needed with community agencies, healthcare professionals, policing as well as government agencies like Children Services and the judicial system.

*"I think a lot more agencies would benefit from more education and awareness about the FASD disability itself…so expectations were more realistic."*

– Service provider, High Level, AB

*"If more of the services were knowledgeable about FASD they could explain services and plans in a way our clients understand."*

– Service provider, Athabasca, AB

*"Getting other professionals to understand clients' needs, presentations, behaviours… with more extreme behaviours doors are shut for clients. Sometimes they look like adults but behave like a 9 year old."*

– Service provider, Calgary, AB

17% of service providers highlighted the need for information sharing in the best interest of the client across all services and programs.

*"It would be great to see a database where you could log-in and just see what other supports are involved in the case."*

– Service provider, Grande Prairie, AB

*"It would be nice if there were occasional case conferences with others agencies to share information and share plans… support each other."*

– Service provider, Fort McMurray, AB

*"Sharing information and permission to share. Following up and working together for updates…improvement is needed with [Family service provider]…they need more information sharing, more transparency and more professional knowledge of FASD."*

– Service provider, Lethbridge, AB

## 3.5: Addiction & Mental Health Services

### Have the individuals with FASD that you work with accessed Addiction and Mental Health services?

All of the service providers interviewed indicated that they have had clients that have accessed Addiction and Mental Health services.

### Have the services been helpful? Why or why not?

When service providers were asked if Addiction and Mental Health services were helpful, 32% of them felt they were not helpful, 26% felt they were helpful and 28% felt they were helpful sometimes.

Of the service providers who felt Addiction and Mental Health services were not helpful, the most common explanation was that the staff were unable to respond to the client's needs in a way that worked for persons with FASD.

*"No, Addiction and Mental Health have not been helpful at all. The model they employ is not conducive to helping people with FASD."*

– Service provider, Lethbridge, AB

*"No they become frustrated with my FASD clients due to their poor cognition. Mental Health services need a better understanding of FASD. A better awareness of how it affects cognition."*

– Service provider, Hinton, AB

*"Not really. Addiction and Mental Health emphasizes CBT and FASD clients don't respond well to it."*

– Service provider, Fort McMurray, AB

*"Not entirely. A lot of our clients have dual diagnosis and there is not enough dual diagnosis services in the province."*

– Service provider, Cold Lake, AB

The second most common explanation was that persons with FASD are often confronted by barriers to service access. Some were turned away from the services because they did not qualify for the service or meet the service entrance criteria, whereas some were unable to complete the steps needed to access the service.

*"Not always. Sometimes addiction services says it's a mental health issue and sometimes mental health says it's an addiction issue."*

– Service provider, Grande Prairie, AB

*"Have not had success accessing Addiction and Mental Health because they don't qualify or can't make it through all steps to be referred or accepted."*

– Service provider, Calgary, AB

*"(They) used to turn people away if they had FASD. Counselling services are not open or accessible to people with FASD. Also the Addiction and Mental Health help for this population is more traditional… these approaches do not work. They would need to be longer-term."*

– Service provider, Lethbridge, AB

*"No not really. Mental health tend to send clients to addictions and there are rarely beds available, so even if we get through the process, there is a waitlist and if we get through the waitlist there are a lot of rules that treatment centres have that our clients don't respond well to. They also don't respond well to treatment models or even leaving their community. Also there is a small window in which they want to go to treatment, so we need to be able to send them now before the window closes. Of course what happens is they say they want to go now but we don't get accepted to treatment until a few weeks later and by then, they no longer want to go."*

– Service provider, Lethbridge, AB

In cases where the service provider felt the Addiction and Mental Health were helpful only some of the time, the most common explanation was that some services were more knowledgeable about FASD than others.

*"Sometimes...it depends on whether staff or program have understanding of the population and needs. If clinicians can focus on self-regulation there can be success."*

– Service provider, Lethbridge, AB

*"More for adults…but some kids are dealing with anxiety and depression. Some successful, some not. Depends on whether or not professionals are FASD informed."*

– Service provider, Lethbridge, AB

*"Depends on practitioners' approach and level of understanding of client needs with FASD. FASD might only be part of issue."*

– Service provider, High River, AB

## How could Addiction and Mental Health (AMH) services be improved?

When service providers were asked how AMH services could be improved, the majority of the responses fell in one of four categories; the first category was FASD education, training and awareness. 36% of the service provider responses indicated there was a need for Addiction and Mental Health staff to gain a better understanding FASD. The service provider responses indicated Addiction and Mental Health staff needed to understand how FASD affects the brain, how persons with FASD require trust and rapport to engage in a clinical relationship, how they required consistent staff and how CBT would does not work with this population due to a compromised capacity for abstract thought.

*"Mental Health services need a better understanding of FASD. A better awareness of how it affects cognition. They need more patience with clients. More long-term service availability for FASD clients."*

– Service provider, Hinton, AB

*"Addiction and Mental Health staff could be improved by staff learning more about FASD…specifically clinical interventions that are applicable and work with FASD."*

– Service provider, Athabasca, AB

*"Mental health clinical staff need training on how to clinically engage clients with brain damage."*

– Service provider, Hinton, AB

*"Addiction and Mental Health is not always helpful because they know there is not a lot they can do for FASD. Persons with FASD don't respond well to their model of care. You can't cure FASD with medication. A lot of these programs and supports are just a bit out of reach."*

– Service provider, Lethbridge, AB

23% of the service provider responses indicated that Addiction and Mental Health would need to identify creative ways of providing services to this population and innovative ways to make current services "FASD friendly." The emphasis being that services needed to be delivered in a way that worked for the patient and that a patient with impaired brain function can't be expected to respond to a one-size-fits-all model of care.

*"To access dual diagnosis services they need more serious diagnoses. But what addiction and mental health doesn't understand is 12 step does not work with FASD…they are concrete thinkers not abstract thinkers. FASD clients actually need their own treatment centres as 12 step doesn't work, FASD clients never last in treatment"*

– Service provider, Calgary, AB

*"These services need to be made 'FASD friendly' similar to the 'second floor program' at [FASD service provider] or [Addiction service provider] in Calgary."*

– Service provider, Fort McMurray, AB

*"Staff need to be creative with how they provide mental health services. CBT does not work for this population. Need to understand or be flexible with appointment scheduling, don't discharge if they miss appointments."*

– Service provider, Lethbridge, AB

*"Addiction and Mental Health needs a better understanding of FASD, they need an FASD-focused model that looks at better ways to engage them. For example, they need a lot of time to develop trust which doesn't work well in the current model."*

– Service provider, Lethbridge, AB

14% of the service providers highlighted the need for flexibility of service access with this population. Addiction and Mental Health service providers need to understand that this population does not cope well with waitlists or wait times. Further, they have difficulty accessing services at the time specified due to impairments with cognition and memory so it makes no sense to close their file or put them back on a waitlist.

*"When these individuals are ready to go to treatment they need to go ASAP….they don't do waiting lists. So if you miss that window…"*

– Service provider, Medicine Hat, AB

*"They definitely need more addictions workers because one person is not enough. FASD clients need a responsive addiction services and will not wait."*

– Service provider, High Level, AB

*"Need to be able to work with individuals with FASD…sometimes they get turned away. Need more flexible approaches to therapy…don't always go into past traumas. Don't close the file if appointments are missed."*

– Service provider, Grande Prairie, AB

*"Difficulties with people needing to miss appointments and follow through…people get taken off lists if they don't comply."*

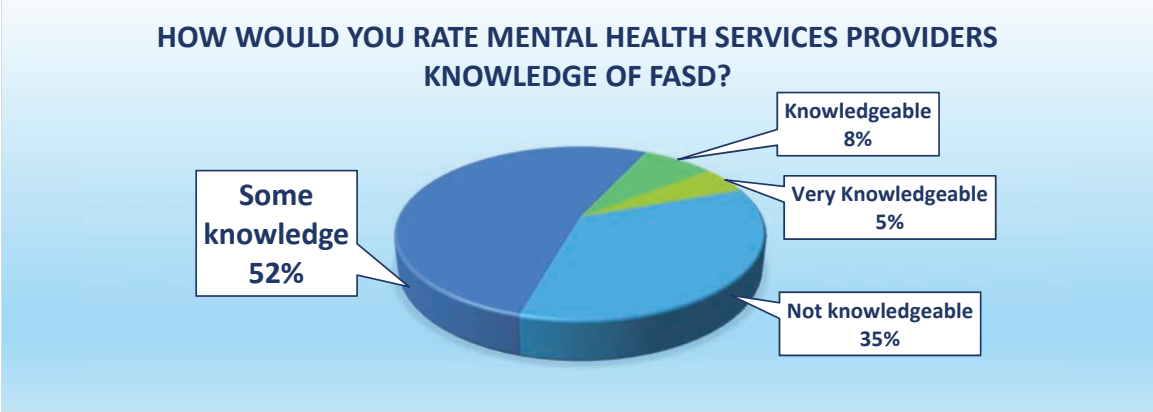
– Service provider, Lethbridge, AB

## 3.6 Community Awareness

If clients have accessed community mental health services, how would you rate mental health service providers' knowledge of FASD between 1 and 4 (with 1 being not knowledgeable and 4 being very knowledgeable)?

See chart 3.6.1: When service providers were asked how they'd rate the FASD knowledge of mental health service providers, 52% said they had "some knowledge", 8% said they were "knowledgeable ", 5% said they were "very knowledgeable" and finally, 35% said they were "not knowledgeable."

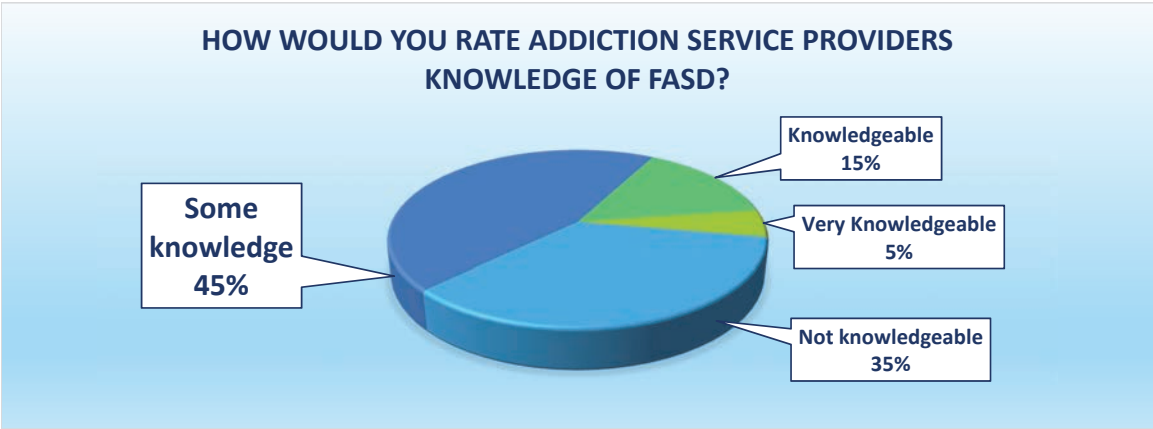
### CHART 3.6.1




If clients have accessed community addiction services, how would you rate addiction service providers' knowledge of FASD between 1 and 4 (with 1 being not knowledgeable and 4 being very knowledgeable)?

See chart 3.6.2: When service providers were asked how they'd rate the FASD knowledge of addiction services staff, 45% felt they had "some knowledge," 15% said they were "knowledgeable," 5% said they were "very knowledgeable" and finally 35% felt they were "not knowledgeable."

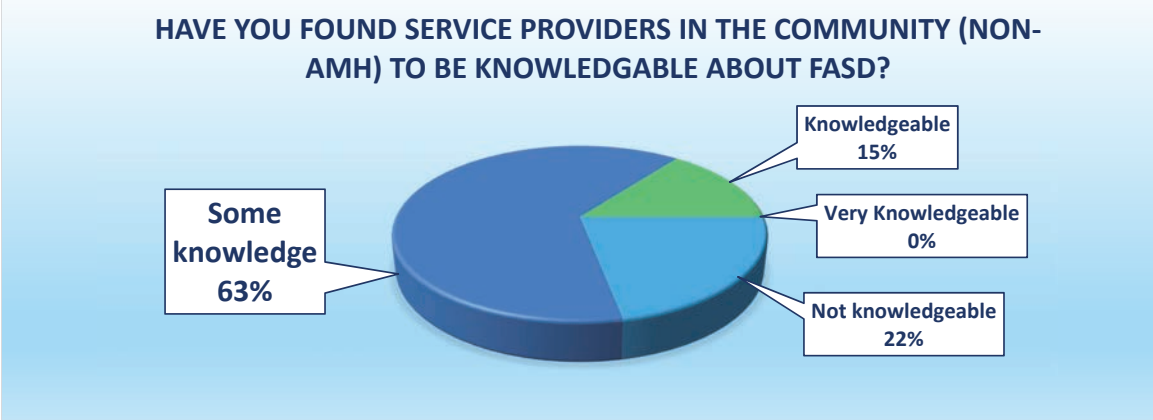
### CHART 3.6.2



## Have you found service providers in the community (not Addiction and Mental Health services) to be knowledgeable about FASD? How would you rate knowledge of FASD between 1 and 4?

See chart 3.6.3: When service providers were asked how they'd rate the FASD knowledge in the community, 63% felt they had "some knowledge," 15% said they were "knowledgeable," 0% said they were "very knowledgeable" and finally 22% felt they were "not knowledgeable."

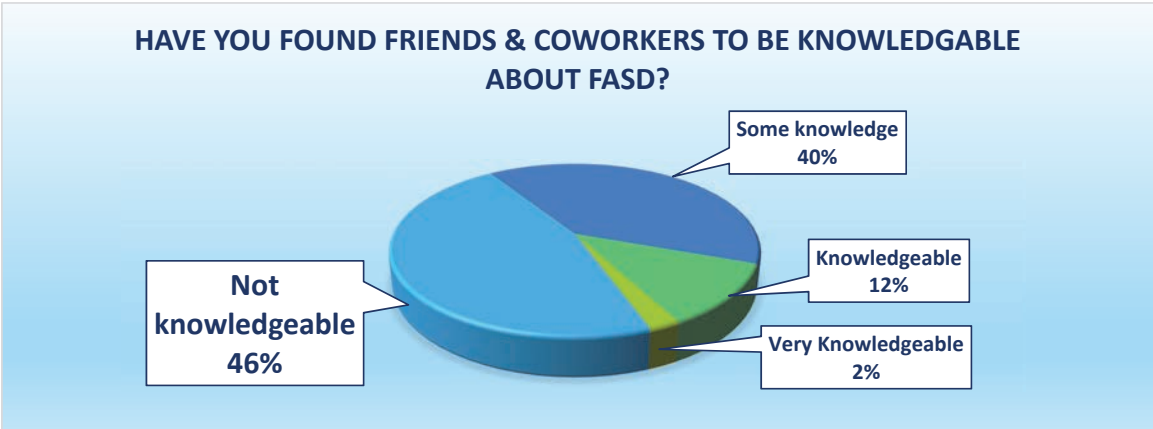
### CHART 3.6.3




## Have you found friends and co-workers to be knowledgeable about FASD? How would you rate other knowledge of FASD between 1 and 4?

See chart 3.6.4: When service providers were asked how they'd rate the FASD knowledge among friends and co-workers, 40% felt they had "some knowledge," 12% said they were "knowledgeable," 2% said they were "very knowledgeable" and finally 46% felt they were "not knowledgeable."

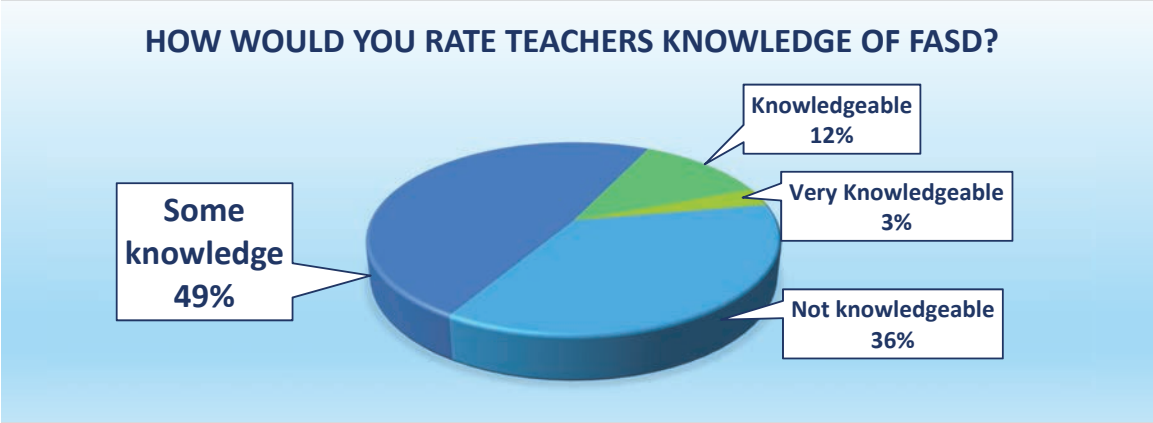
### CHART 3.6.4



## How would you rate teachers' knowledge of FASD between 1 and 4?

See chart 3.6.5: When service providers were asked how they'd rate the FASD knowledge among teachers, 49% felt they had "some knowledge," 12% said they were "knowledgeable," 3% said they were "very knowledgeable" and finally 36% felt they were "not knowledgeable."

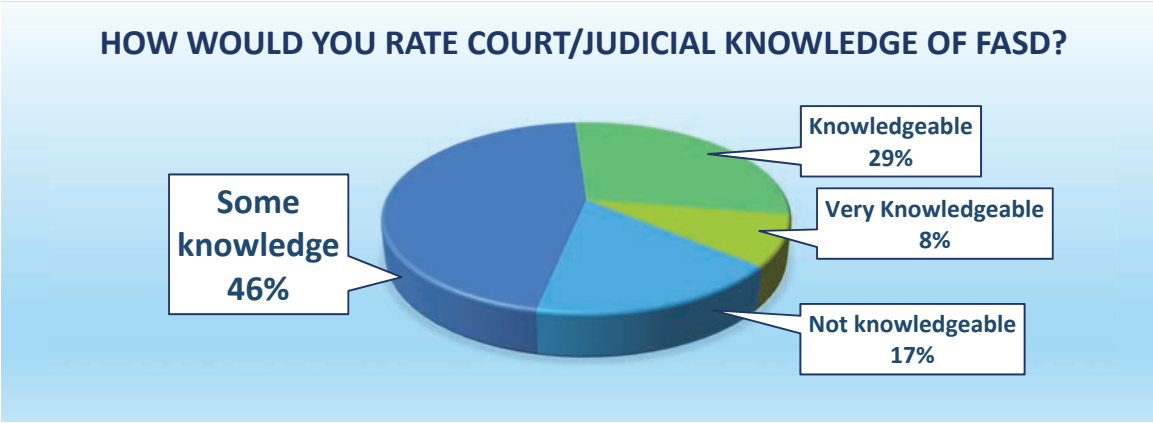
### CHART 3.6.5




## How would you rate court/judicial services' knowledge of FASD between 1 and 4?

See chart 3.6.6: When service providers were asked how they'd rate the FASD knowledge among court and judicial services, 46% felt they had "some knowledge," 29% said they were "knowledgeable," 8% said they were "very knowledgeable" and finally 17% felt they were "not knowledgeable."

### CHART 3.6.6



## 3.7 Barriers & Challenges

### What is the most difficult thing to manage with clients with FASD and why?

When service providers were asked what the most difficult thing to manage was with their clients, the list of responses was vast to say the least. However the most common responses revolved around time management, case complexity, impulsivity, housing or homelessness, daily living skills, money management and interpersonal relationships.

21% of the service providers indicated that dealing with their clients' poor time management skills was one of the most challenging parts of their work.

*"There is a lot of crisis management. There is a lot of problems with time management. They have poor adaptive skills, poor life skills, behaviour management and mental health."*

– Service provider, Medicine Hat, AB

*"Executive functioning issues…like time management, awareness of space, lack of understanding of societal norms and values…people don't understand their behaviours and why."*

– Service provider, Calgary, AB

14% of the service providers indicated that it was poor day-to-day living skills and money management that caused the most challenges in the work they do with FASD populations.

*"Managing systems. Money management (for clients). Relationships. People have challenges with things like day-to-day operations and tuning in emotional responses."*

– Service provider, High River, AB

*"Daily living skills. They really struggle with this. They have to be constantly reminded for appointment times and dates. Appropriate boundaries and impulse control. There is no cookie cutter approach to FASD spectrum they are all unique with unique challenges."*

– Service provider, Cold Lake, AB

A further 12% of the service providers indicated it was the complexity of the individual cases that was one of the most challenging part of their work.

*"The complexity of their case. Persons with FASD have very complex problems that normal functioning people would struggle with…let alone someone with cognitive impairments."*

– Service provider, Hinton, AB

*"Complex cases…clients where they've been in child welfare. If they haven't had a strong relationship with trust or connection. It's challenging to build sense connection so they can buy-in and have some success or stability"*

– Service provider, Medicine Hat, AB

Another 12% of the service providers indicated it was the impulsivity of their FASD clients that made their work challenging.

*"I would say impulsivity. It takes us a long time to set up plans and certain resources and they can destroy it in a day with impulsive behaviours."*

– Service provider, Calgary, AB

*"Each person comes with their own unique set of challenges that they are facing…a client who was very angry, challenging to support, behavioural presentations, impulsivity. Helping manage impulsivity and decision-making."*

– Service provider, Calgary, AB

9% of the service providers indicated that housing and homelessness was a major source of their work-related challenges.

*"Addiction and homelessness. Homelessness sometimes causes addiction and sometimes the addiction causes homelessness."*

– Service provider, Lethbridge, AB

*"Adult clients…its housing and budgeting with money. Also their friends can cause issues when they get housed. A lot of racism issues with Indigenous clients with FASD."*

– Service provider, Lethbridge, AB

## What are the strengths in the clients you work with that have FASD and what are the strengths of the families?

Service providers were asked what they felt the strengths of their FASD clientele was and again, there was a wide range in responses but the majority focused on resiliency, compassion, humour, creativity and their willingness to learn.

40% of the service provider responses spoke to their client's resiliency, perseverance and persistence.

*"They let you know how they are feeling. They are very resilient…most of my clients have endured lifetimes of extreme trauma that would crush normal people."*

– Service provider, Hinton, AB

*"Incredibly resilient and resourceful. Many clients have survived many things that…I don't know how they did it. There are also functional strengths…FASD is scattered."*

– Service provider, Calgary, AB

*"Resiliency to keep going despite being shut down and mistreated and misunderstood by professionals. They still want better lives for themselves."*

– Service provider, Calgary, AB

Another 16% of the service provider responses spoke to how caring and compassionate their clients are with family and friends.

*"They have huge hearts. They always want to help people or make them happy so this is sometimes their biggest weakness because people take advantage of them. Also their resilience. Their lives could be falling apart and they don't let it bother them."*

– Service provider, Athabasca, AB

*"Very kind and caring; willing to help. Always supportive to friends and family. Good sense of humour. Very resilient"*

– Service provider, Medicine Hat, AB

*"They are very generous…often giving away their belongings and money."*

– Service provider, Hinton, AB

Another 13% of the service provider responses pointed towards their client's good sense of humour and optimism.

*"They have very outgoing happy clients. They are always happy to accept supports."*

– Service provider, Westlock, AB

*"They often have good senses of humour. They are often artistic. They often have big dreams and plans."*

– Service provider, Medicine Hat, AB

A further 13% of the services provider responses highlighted their client's creativity and artistic expression.

*"Creativity. It's a self-expression that evolves when communication skills are limited. Also their sensitivity, resiliency, positivity and optimism; they stay positive under circumstances that would crush most people."*

– Service provider, Athabasca, AB

*"A lot of my clients are creative…they like art and puzzles…taking things a part and resembling them. A lot of my clients have been or are in foster care and for what they have gone through they show remarkable resilience."*

– Service provider, Cold Lake, AB

Finally 11% of the service providers spoke to their client's willingness to learn new things and to work very hard.

*"Persons with FASD are always very keen to learn about FASD and how affects them, their brain and their behaviours."*

– Service provider, Grande Prairie, AB

*"They are always willing to learn and try their hardest. They are very caring people."*

– Service provider, Grande Prairie, AB

# 3.8 Opportunities for Service Enhancement

## What would help your clients with FASD manage home and community better?

When service providers were asked what would help their clients manage at home and in the community better, 34% of the service provider responses indicated that more community-based supports and daily one-on-one supports were what was needed.

*"They all need their own daily support worker to help manage their time and organize their lives in terms of health, schedules, etc. Also FASD clients need a lot more services that look at supported parenting for people with FASD; existing parenting supports know very little about FASD."*

– Service provider, Calgary, AB

*"PDD-style supports…this means more day-to-day supports, how to budget, how to buy groceries, how to do laundry."*

– Service provider, Athabasca, AB

*"About 70% of client are Indigenous and about 30% are non-Indigenous. A lot of the Indigenous clients don't have natural or family supports that they can access. We need more community supports to address that gap. We need to establish more housing resources and housing supports as they are not always good tenants and get in trouble with landlords through damage or unpaid rent."*

– Service provider, Grande Prairie, AB

A further 20% of the service provider responses indicated that better FASD awareness and training was needed in the community to better support persons with FASD.

*"More community awareness of FASD. More community support for FASD disabilities. The hospital is not very helpful and clients are often treated poorly by staff. There should be a 24 hour on-call service that can respond to crises involving a person with FASD. One client lost his keys and stayed at 7/11 to get out of cold. Another client was arrested and thrown in remand when he couldn't speak up and advocate for himself."*

– Service provider, Edmonton, AB

*"More access to counselling-staff and clinicians who understand FASD and help those clients and families."*

– Service provider, Lethbridge, AB

*"More community awareness of FASD and how it effects people. More community knowledge of the FASD population in Fort Mac. A lot of people think it's only an Indigenous problem."*

– Service provider, Fort McMurray, AB

*"More training for people that provide support in community. A lot of services will not accept you as a client if you missed appointments. Well FASD clients are famous for this."*

– Service provider, Edmonton, AB

Another 20% of the service provider's responses indicated that services and supports need to be flexible as well as accessible to clients with FASD.

*"A lot of my clients that live on reserve and don't have access to the supports that my clients in Cold Lake do…I only see them monthly due to things like money and transportation. So I have to go to them like once a month …instead of weekly like people here see me."*

– Service provider, Cold Lake, AB

*"There is no PDD office in High Level even though a lot of clients are approved for PDD supports. About 90% of our clients have been approved for PDD but there is no service to deliver PDD supports."*

– Service provider, High Level, AB

*"Being able to get into programs- sometimes individuals are screened out/ turned away because of FASD."*

– Service provider, High River, AB

*"I think if there was a lot more flexibility in the way services were provided. In healthcare it's not being kicked out for being late. In justice it would be more of healing circle or restoration justice model."*

– Service provider, Edmonton, AB

Finally, 16% of the service provider responses indicated that safe, stable and affordable housing is what is needed to support persons with FASD in the community.

*"Stable Housing. They have real problems maintaining tenancy. They need harm reduction housing because they don't always understand the consequences of things they do and get evicted."*

– Service provider, Athabasca, AB

*"Housing…we're always trying to find safe and affordable housing. Particularly for youth clients when the family relationship is broken down. Supportive roommates. Supportive living and supportive housing... housing that is not the "Sober model."*

– Service provider, Calgary, AB

## If you can change anything about the services that are provided for individuals with FASD and their families, what would you change?

The service providers were asked what they felt they would change in the services currently available to individuals with FASD and their families. The responses seemed to revolve around three major themes: accessibility, more services and supports and FASD awareness and training.

27% of the service providers indicated that services needed to be more accessible to persons with FASD. Some service providers indicated that essential support services were difficult to access in terms of availability or location, while others felt services were difficult to access due to restrictive entrance criteria.

*"I would increase access to [Justice service provider]. Because of impaired executive functioning they are often non-compliant with current probation orders and if the access to [Justice service provider] is restricted one charge often snowballs into multiple charges. It is an ineffective waste of tax dollars to have people sent to jail for breaking curfew and it happens all the time."*

– Service provider, Hinton, AB

*"Respite for families is very important and needs to be easier to access. Without caregiver respite, the caregivers burn out and the placement breaks down. Also respite providers that provide respite in-home because FASD clients do not adapt well to strange environment or changes to structure."*

– Service provider, Grande Prairie, AB

*"We need to be able to do assessments sooner and we need to be doing them locally instead of getting up at 5 am and driving all the way to Edmonton."*

– Service provider, Edmonton, AB

*"Ultimately PDD needs to move the IQ level up or change the access criteria all together so FASD clients could access these services. There are 10 brain domains…IQ and academic is only one... FASD typically have deficits in memory, relationships, social and emotional regulation, comprehension."*

– Service provider, Athabasca, AB

*"Take away the PDD 70 IQ stipulation… so people can access funding and help."*

– Service provider, Lethbridge, AB

A further 24% of the service provider responses indicated they would like to see a rise in the level of services and supports currently available. To some, an increase in staff was what was needed, to others it was the amount of services provided and the length of time those services would be made available.

*"We need more staffing capacity. We are always struggling with meeting demand… so we need more funding for staffing. We also need to recognize the value in this service and pay accordingly. Some of my staff get paid the same as a McDonald's worker. So why would they work in this field? It should be recognized as a population of health needs like PDD or seniors."*

– Service provider, Lethbridge, AB

*"Increase the amount of services they get in terms of how much and how long they are able to access services."*

– Service provider, Medicine Hat, AB

*"I wish we had more time to work with them; so I guess I wish we had more staff."*

– Service provider, Fairview, AB

*"I don't think there is enough funding to help people with FASD. It is a lifelong disability that will require expensive support."*

– Service provider, Edmonton, AB

Finally, 22% of the service providers indicated that they would like to see an increase in FASD awareness. Some service providers identified specific services that needed more awareness, while others mentioned specific elements of training needs.

*"More training and awareness for court and probation staff."*

– Service provider, Westlock, AB

*"I'd like to see more police staff taking FASD training. I'd like to see more staff and less burnout and turnover."*

– Service provider, High Level, AB

*"More Addiction and Mental Health providing services specifically for this population…the 12-step model doesn't work with this population. We need more treatment options that work. We need more FASD informed options for services, especially Addiction and Mental Health… as most of these individuals will encounter addiction and mental health challenges."*

– Service provider, High River, AB

*"More understanding of not just FASD but the life experiences of persons with FASD. More awareness would create more empathy. There is a real deficit of understanding and empathy when it comes to a person with FASD"*

– Service provider, Hinton, AB

*"I would change the stigma associated with FASD in the community. FASD awareness that teaches professionals to be more patient and understanding."*

– Service provider, Hinton, AB

*"Services being able to understand the dynamics of clients with FASD. Services and program expectations about people showing up to appointments and then closing a file…and denying services."*

– Service provider, Lethbridge, AB

## What are other ideas you might have about what would make it better for individuals living with FASD and their families?

The service providers were asked for additional ideas that they thought might help persons with FASD and their families. Again, the responses seemed to focus on three main areas which were awareness, community programming and housing.

While awareness was mentioned as a theme in the previous question, there appeared to be a greater emphasis on the need to tackle stigma at the community level in this one. 33% of the service providers mentioned some form of community awareness initiative with almost half of them specifying the need to address stigma.

*"I think a standardized FASD training platform would be helpful to ensure people who work with FASD clients have at least basic understanding. A standard training platform that could be provided to teachers, police, court staff, ambulance and health staff…it could provide a level of basic understanding."*

– Service provider, Edmonton, AB

*"We need more community-based awareness and more FASD training. We also need more positive messaging regarding FASD. They need to tackle stigma not support it."*

– Service provider, Edmonton, AB

*"More social awareness out in community…education and awareness to understand the way people with FASD are...this will reduce the stigma that FASD has on individuals."*

– Service provider, Calgary, AB

*"Provincially we still need more agencies that don't rely on numbers and criteria… we need more FASD awareness and training…we need a "let's talk" campaign for alcohol and FASD…we need to deal with shame and stigma."*

– Service provider, High River, AB

A further 21% of the service providers indicated that more community programming was needed to support persons with FASD. Service providers mentioned much needed community services like supported education and employment, recreational programming and community support.

*"They need more supportive employment services where people understand FASD. FASD clients are hard workers but they get stressed out and don't cope well with stress. Employers need to know this and understand this."*

– Service provider, Calgary, AB

*"Community programming for people with FASD…things like art classes, game nights…hosted by people who understand FASD…so noise is controlled, light is controlled… it's not overloading senses of FASD kids."*

– Service provider, Cold Lake, AB

*"More opportunities for education and training with FASD catered programing. They get really self-conscious so more teachers with FASD training."*

– Service provider, Lethbridge, AB

Finally, 14% of the service providers again mentioned housing as a priority for persons with FASD. The majority focused on supported housing with support staff and daily programming. One service provider specified the need for a stand-by bed that could be accessed in times of crisis.

*"More supported housing models for people with FASD…that have trained staff and support on-site, operating like a multi-disciplinary team."*

– Service provider, Edmonton, AB

*"More access to housing for both youth and adults with FASD due to inability to maintain ongoing housing"*

– Service provider, Lethbridge, AB

*"(Housing with) housing supports included…daily living supports and programs…with one-on-one key workers."*

– Service provider, Lethbridge, AB

*"We need a facility with a crisis bed; a place for them to go when they are kicked out of their living space."*

– Service provider, Lethbridge, AB

## Is there anything else you would add that has not yet been discussed?

The final question in the service provider interview was included as a final opportunity to express concerns about issues that the interview template may have overlooked. Although there were a few notable differences, the service provider responses to this question seemed to reiterate the importance of FASD awareness and stigma, FASD education and training; Addiction and Mental Health service improvement; housing availability and availability of FASD assessments.

71% of the service providers indicated that greater effort was needed to improve public and professional awareness of FASD.

*"Health and medical staff need FASD education and awareness because a lot of the communication they have with clients has been offensive or condescending. Bedside manner needs improvement when it comes to patients with FASD."*

– Service provider, Cold Lake, AB

*"Access to funding for (FASD) training and education is always lacking. Other areas get good access to staff development and training and it helps them cope; it helps retain staff; it stops burn out. So it would be nice to see some consistency there."*

– Service provider, Fort McMurray, AB

*"There needs to be a class on FASD at post-secondary institutions for people who are in human services so that doctors, nurses, lawyers, teachers and services gain a full, comprehensive understanding of FASD."*

– Service provider, Hinton, AB

More than half of those that advocated for further public and professional FASD awareness mentioned the need to address the stigma attached to FASD.

*"We need a targeted stigma-reduction campaign. We need to get away from just emphasizing prevention. We need to also focus on assessment, treatment and support services and ultimately the importance of societal compassion."*

– Service provider, Athabasca, AB

*"I have a client who says 'I have FASD can you explain that differently to me please'…this took years to get to this point. So once the stigma and shame is taken away they can actually ask for help without fear of judgement and get the services they need."*

– Service provider, High Level, AB

*"General population has needs for understanding and empathy of adversity. Tolerance and understanding and the removal of stigma, especially with biological moms, and kids or adults living with FASD and other diagnoses."*

– Service provider, Lethbridge, AB

17% of the service providers, again raised concerns about Addiction and Mental Health services. The concerns were related to inappropriate treatment intervention, as well as access to treatment services and supports.

*"Addictions services needs to take a serious look at how they deliver services to persons with FASD. They need to be more flexible with impulse control. They need to understand FASD populations don't get choice and consequence. They are expected to grasp concepts that they would have severe difficulty in understanding and nobody to help them understand it. There needs to be more trauma-informed service delivery. Almost all of our FASD clients have been physically or sexually abused and quite often present with self-harming or suicidal behaviours. They make poor and often dangerous choices so they are always being beaten up or assaulted. This is why they need lots of one-on-one support."*

– Service provider, Edmonton, AB

*"It's extremely difficult to get FASD clients into addiction treatment. Addiction treatment providers are not willing or able to handle FASD behaviours and deny access."*

– Service provider, Medicine Hat, AB

*"I would like to see more appropriate addiction treatment programming for persons with FASD...more appropriate transition and discharge….and more supports in the community to help them after treatment."*

– Service provider, High Level, AB

14% of the service provider responses highlighted housing as a concern. The service providers indicated that transitional housing, affordable housing and supported housing were often unavailable or existing housing resources were not appropriate.

*"There are a number of our clients who have a diagnosis and are on AISH but they are homeless. This is due to a lack of affordable housing but it's also behavioural. They damage properties or their guests damage the property and eviction ensues. We try to offer support to landlords but they are quite often reluctant; they just evict. Also there are ethics… we can't in good conscience put a potentially violent client or a substance abusing client in the basement of a senior couple. There is a huge need for a supportive housing where eviction isn't the first port of call."*

– Service provider, Lethbridge, AB

*"More supported housing models for persons with FASD that have trained staff and support on-site, operating like a multi-disciplinary team. We need transitional housing that could act as a safety net when FASD clients have a crisis like eviction or they're released from treatment or jail and they have nowhere to go. Often persons with FASD are leaving an abusive situation and need immediate shelter."*

– Service provider, Edmonton, AB

*"Homelessness is huge here. They closed the only shelter. Even when a client has AISH and is in an apartment; they will 'payback' friends by letting friends and family crash there and eventually they get kicked out too. We are always in crisis response...in fact when we hear they have been put in the correctional we often breathe a sigh of relief because we know they will be warm and fed."*

– Service provider, High Level, AB

12% of the service provider responses again highlighted the need for more assessments, stressing that without the assessment clients don't have a diagnosis and often falling through the cracks without appropriate services and supports.

*"We are funded for 10 child assessments and 4 adult assessments per year. The waitlist is like 6 to 8 years so I would think 50 child assessments per year would be more appropriate."*

– Service provider, Medicine Hat, AB

*"[Financial support service] wants these people to work but they are not always capable of holding down a job. Without a diagnosis they can't get AISH so they end up on the streets, living under bridges or living in tents or abandoned buildings. Drugs use and criminal activity tends to increase. Rural communities need more resources. There are no shelters here and people with FASD often refuse to leave community so they end up in tents."*

– Service provider, Athabasca, AB

Beyond the themes highlighted above, there were important statements made that may warrant further inquiry. One such statement related to the frequency of persons with FASD being incarcerated. Throughout the interview process, a number of participants mentioned clients with FASD being incarcerated, some on a regular basis.

*"I believe 65%-70% of incarcerated individuals are somewhere on the FASD spectrum. We need a study of what the real numbers are. We need to develop a way of assessing them while they are incarcerated. A screening tool so that we can assess them."*

– Service provider, Medicine Hat, AB

Another statement exposed a rather innovative community approach that aims to improve communication, collaboration and coordination of community-based organizations. In this community collaborative model, persons with FASD benefit from a more multi-agency approach in the provision of supports, services and resources.

*"We have a "Collective Wisdom" group which is comprised of representatives from a number of different CBO's. We have a release of information and confidentiality agreement so we can discuss individual cases and we sometimes will invite the Crown or PDD or whoever if we think they can contribute to the care plan."*

– Service provider, Lethbridge, AB

# Section 4: Perspectives – Caregivers of Persons with FASD

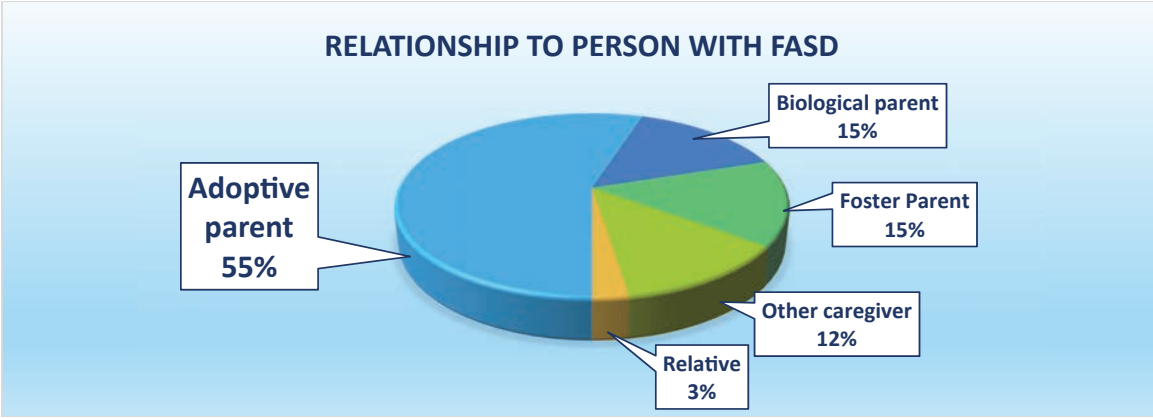
While FASD service providers were able to illustrate the challenges involved when supporting persons with FASD and their families, caregivers were able to illustrate their day-to-day challenges in home and in the community when caring for a person with FASD.

## 4.1: Demographics

The project team interviewed a total of 37 people who identified themselves as a caregiver for a person or persons with FASD. For the most part these caregivers were identified through the FASD network or an affiliated FASD service provider, however, a small number of caregivers contacted us directly after hearing about the project through word of mouth.

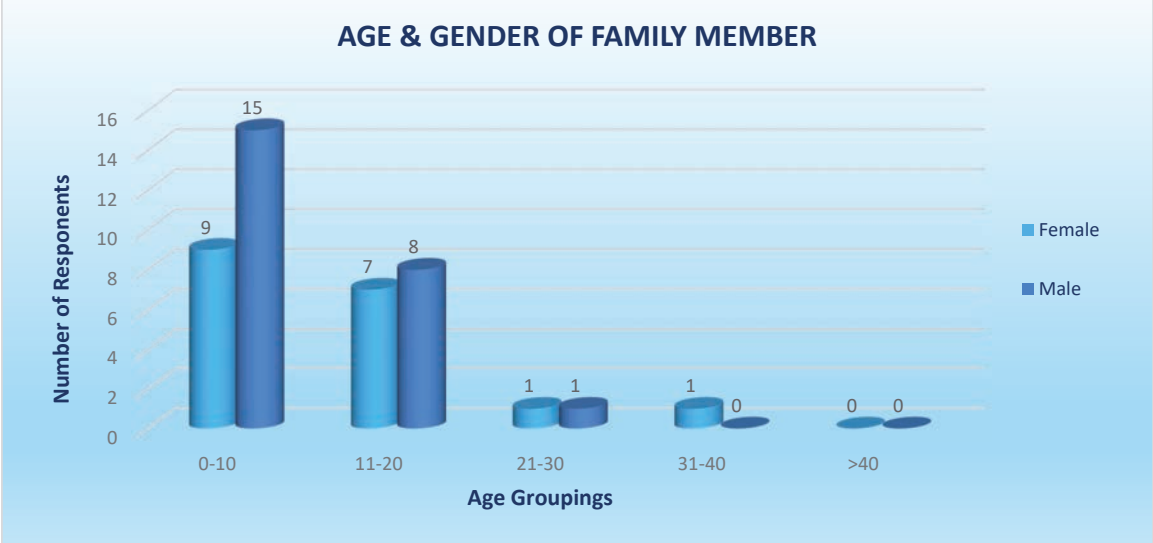
See chart 4.1.1: The majority of the caregivers interviewed were the adoptive parent of a person or persons with FASD. It was clear all the caregivers we interviewed cared deeply about their family member, but it became apparent very early on that adoptive parents were particularly passionate about their role as an advocate for their family member. Accordingly, it comes as little surprise they make up the bulk of the caregiver sample pool having volunteered to share their story.

### CHART 4.1.1



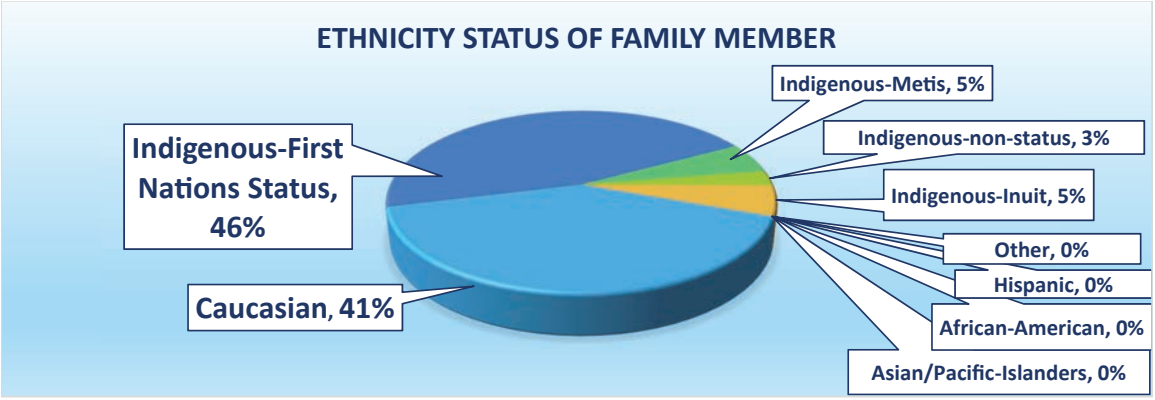
See chart 4.1.2: The vast majority (57%) of the caregivers interviewed cared for children under 10 years old. A further 36% of the caregivers are caring for children over 10 years of age and young adults up to 20 years of age.

## CHART 4.1.2




See chart 4.1.3: Looking at the ethnicity of the family members, it is clear the majority of the family members are status Indigenous persons (46%). This is followed by Caucasian making up 41% of the participants. But if one considers the addition of Metis, Non-Status and Inuit, the percentage of Indigenous persons rises to 59%.

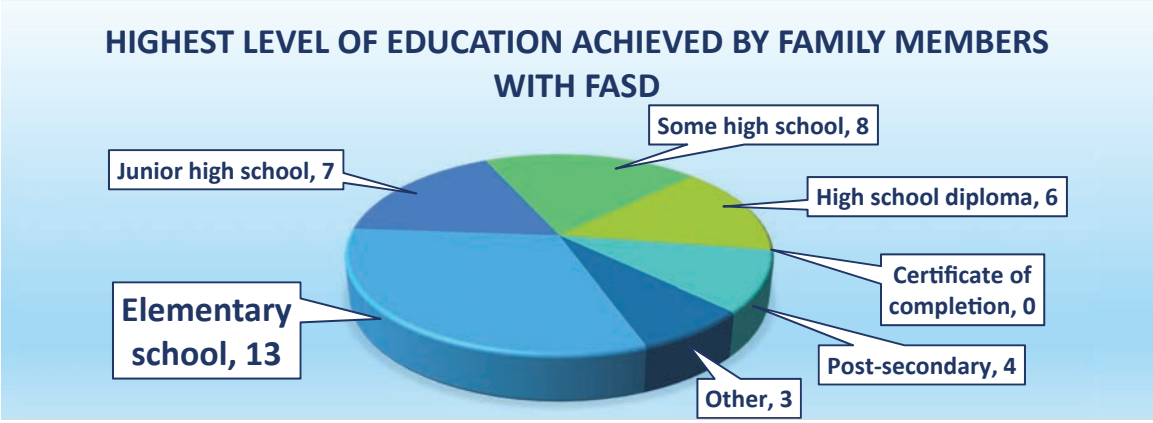
## CHART 4.1.3




See chart 4.1.4: Looking at the highest level of education achieved by family members with FASD, we immediately see 13 of the caregivers indicated their family member completed elementary school. It should be noted that of this 13, all but one of the family members were elementary age school children.

It should also be noted that the level of education achieved by adult family members in this graph is higher than the levels of education achieved by adults in the Persons with FASD section of this report (Section 5). This is mostly likely attributed to the fact that the adults considered here are still very much connected to the caregiver and the support that entails, whereas the adults discussed in section 5 of this report were more often estranged from the caregivers and without familial supports.

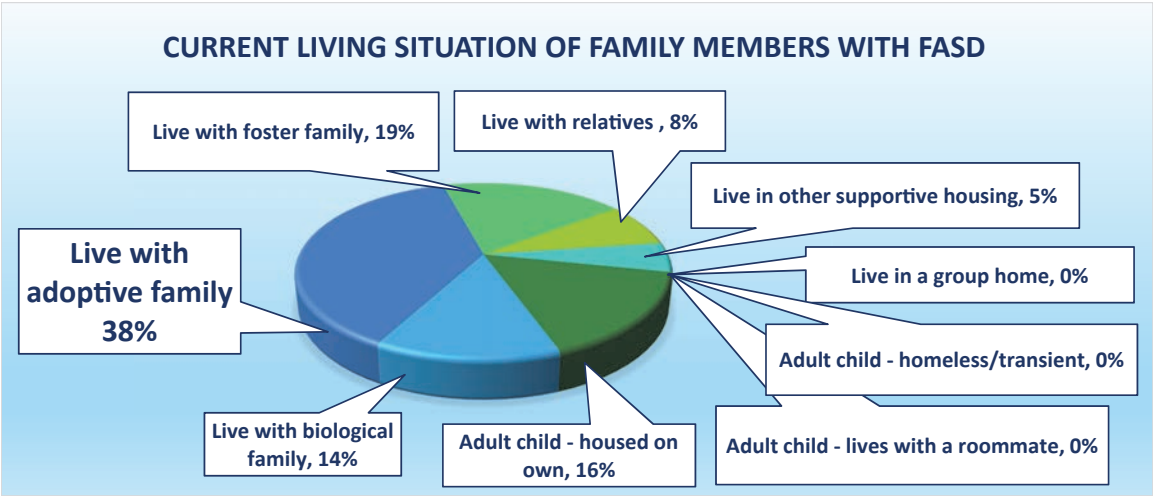
## CHART 4.1.4




See chart 4.1.5: Looking at the current living situation of the family members with FASD, it is evident they most often reside with their adoptive parents. It is interesting to note none of the caregivers identified their family member as homeless or transient (0%).

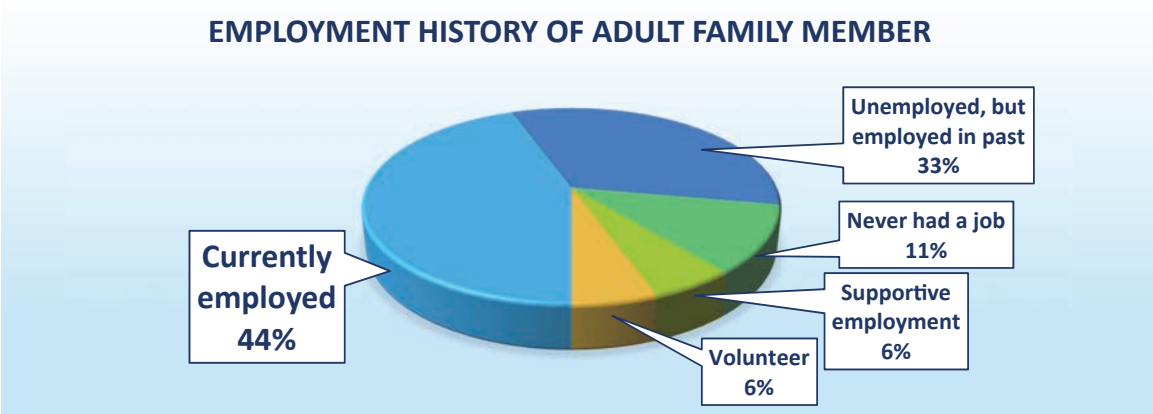
In section 5 of this report, we examine adults who identify as having FASD, many of whom were estranged from their biological families, their foster families and or their adoptive families. While this cohort includes only 15 adults, the rate of homelessness or transient living in that cohort is much higher, speaking to the security and stability caregivers bring to the lives of persons with FASD. It also speaks to the importance of caregivers being and feeling supported with the care of their family members, so that the placements do not deteriorate or break down, resulting in homelessness.

## CHART 4.1.5



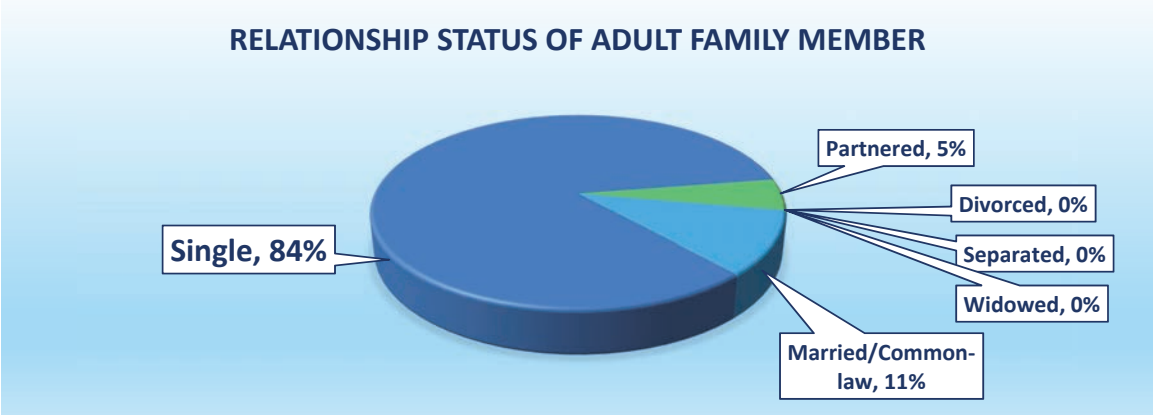
See chart 4.1.6: Similar to the current living situation graph above, we see the rate of active employment and volunteering with these 15 adults is much higher than the adults with FASD examined in the next section. In the caregiver interviews, there were countless stories of caregivers being advocates for the various needs of their family member; constantly mobilizing supports and services. When we compare this rate of adult employment with the rate of employment in the adults with FASD cohort, its clear employment for a person with FASD becomes far more attainable and sustainable when there are numerous supports in place for the individual, namely the support of a caregiver.

## CHART 4.1.6




See chart 4.1.7: Like the two previous graphs, the relationship status of the 15 adults still connected to their caregivers were quite different from the adults with FASD discussed in the next section. The cohort still connected to their caregiver tended to be single but had higher rates of reported partnered, married or common-law relationships. Similarly, the cohort still connected to their caregiver tended to have lower levels of widowhood, separation or divorce than the adults with FASD examined in the next section.

## CHART 4.1.7



# 4.2: FASD Assessment & Diagnosis

The vast majority (88%) of the caregivers had a family member who has been assessed for FASD. 75% of the caregivers indicated that their family member had a confirmed diagnosis of FASD.

## How long did you have to wait for an assessment?

See chart 4.2.1: When asked how long they had to wait for an FASD assessment, 52% of the caregivers indicated they waited over a year while 26% of the caregivers indicated they waited between 1 to 3 months.

### CHART 4.2.1

## Has receiving a formal diagnosis been helpful? Why or why not?

When asked if a formal FASD diagnosis has been helpful, all of the caregivers who had family members assessed answered "Yes."31% of the caregivers indicated that the assessment resulted in getting more services and supports that helped the family and the family member.

*"Yes. We couldn't get any help with her. After the assessment I was able to get help and eventually AISH."*

– Caregiver, Edmonton, AB

*"We didn't really care about the diagnosis, but it explained a lot of her behaviour; I mean she couldn't read until grade 5. We were also able to access respite care after the diagnosis."*

– Caregiver, Edmonton, AB

Another 29% of the caregivers indicated that the diagnosis gave them a better understanding of the child's struggles, behaviours and a better awareness of the family member's needs.

*"It was helpful. I could now make sense of behaviours. I could now change parenting strategies; talk to school, etc."*

– Caregiver, Red Deer, AB

*"Yes because it has helps our daughter answer questions about herself, her brain, her behaviour etc. It paints a clearer picture of why things are happening."*

– Caregiver, Kehewin Cree Nation, AB

*"Yes. It gave us some language to be able to talk to her and understanding what we were dealing with. It also helped us access resources and helped her understand her own difficulties."*

– Caregiver, Edmonton, AB

A further 23% of the caregivers indicated that diagnosis provided access to additional educational supports that supported the family member in school.

*"Yes. Because we were able to use the diagnosis to access educational supports from the child and family agency. It was also helpful for her to understand challenges she would face in life."*

– Caregiver, Red Deer, AB

*"Yes. It got her half time aide at school; that aide is shared with other students in her class… it also helped us get the disability tax credit which helped out a lot. Also got us into a caregiver support group."*

– Caregiver, Grande Prairie, AB

Finally, 17% of the caregivers indicated the diagnosis meant they could access additional financial supports that could support the family in meeting the family member's needs.

*"Yes. Now the school has extra staff going into help him; like a counselor and an SLT (speech language therapist). Our family allowance also went up $200."*

– Caregiver, Rocky Mountain House, AB

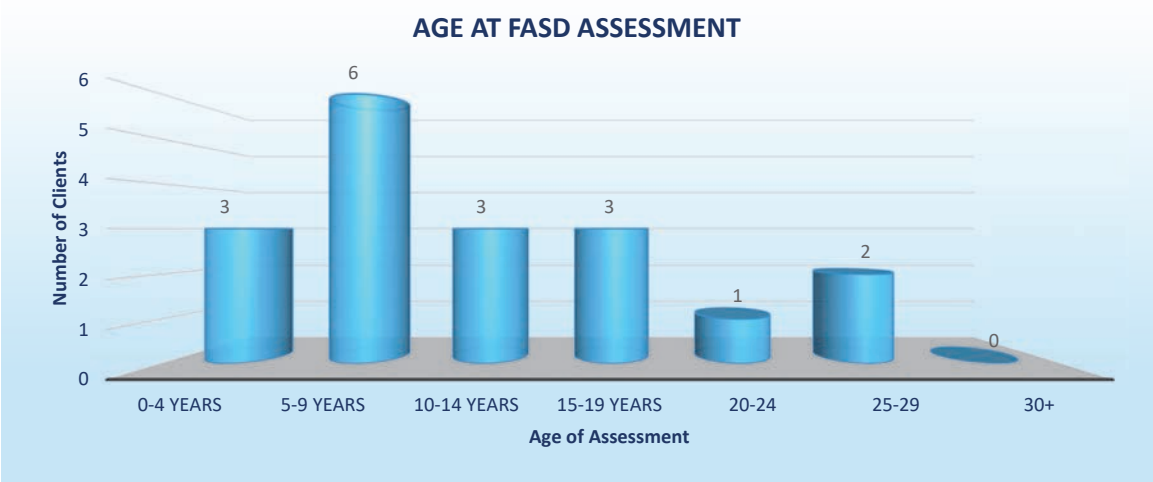
*"Yes. Now we could apply for AISH. You can't do anything without diagnosis."*

– Caregiver, High Level, AB

## How would a diagnosis have helped your child and family now or when your child was younger?

See chart 4.2.2: Due to the complexities of adoption, foster parenting and extended family care, a number of caregivers had difficulty specifying the exact age their family member was diagnosed with FASD. Further, a number of the caregivers were still on an active waitlist for an FASD assessment.

### CHART 4.2.2




When asked how an earlier diagnosis may have helped their child and their family, 37% of the caregiver responses indicated it would have been helpful for accessing educational supports.

*"Yes because of the supervision piece as parents…especially when she was younger…I might not have left her alone etc.…also her schooling, they (teachers) would have helped her with unstructured work or independent work if they had known...I could have helped and been more vigilant…more contact with the school."*

– Caregiver, Edmonton, AB

*"It (an earlier diagnosis) would have avoided a lot of frustration and confusion. The preschool told us that she would have significant difficulties in Kindergarten. She could not cope with a larger class. An educational psychologist monitored her in kindergarten and stated she was taking up 90% of the teacher's time. After diagnosis she got her PUF (program unit funding) funding and she was able to have an education assistant placed in the classroom."*

– Caregiver, Millet, AB

Another 37% of caregiver responses indicated that the diagnosis would have been helpful in trying to understand or explain the child's struggles to other family members.

*"If he had a diagnosis sooner it would have helped his previous caregivers understand his behaviours. It may have helped his school."*

– Caregiver, Grimshaw, AB

*"Definitely. She needed a lot of help with school and homework. She was constantly fighting with siblings because she got more attention…needed more help. It put a lot of pressure on me and the family."*

– Caregiver, Edmonton, AB

17% of the caregiver responses indicated that the diagnosis was not always helpful, with 2 respondents indicating the diagnosis may even have been detrimental because of the stigma associated with it.

*"I feel like if they had a diagnosis earlier they both would have been treated differently; the stigma would have limited their supports."*

– Caregiver, Red Deer, AB

8% of the caregiver responses indicated the diagnosis would be helpful in terms of accessing health services and medications.

*"I would be able to access more health services…educational supports…respite services...it would also help explain her needs to education staff."*

– Caregiver, Edmonton, AB

*"More support earlier would be have helped, especially with medications and maybe different medications. It would have helped with understanding his behaviours."*

– Caregiver, Lacombe, AB

## Who explained FASD to you and how?

When caregivers were asked who explained the FASD to them it was clear the vast majority (43%) of them learned about FASD through their work or professional practice, through community agencies offering services or programs to individuals with FASD.

*"[FASD service provider] come to our community to teach a class called FASD 101. It was really well done. It helped a lot of our staff understand the residents."*

– Caregiver, Kehewin Cree Nation, AB

*"I learned about it in school (trained OT) but I also learned a lot through adoption seminars and fellow adoptees."*

– Caregiver, Edmonton, AB

A further 23% of the caregivers indicated they were self-taught. Many of the caregivers spoke of attending conferences and seminars, while some spoke of reading FASD books, resources or online websites.

*"Mostly own research about this emerging diagnosis, I looked up info, did my own work."*

– Caregiver, High Level, AB

*"I think most of it I learned on my own, research I have done independently."*

– Caregiver, Edmonton, AB

Another 14% said it was the staff from the FASD assessment team who first explained FASD to them.

*"Probably Dr. A.; she was very thorough."*

– Caregiver, Athabasca, AB

*"T. and others involved in the assessment all sat us down and went through a final report."*

– Caregiver, Red Deer, AB

11% of the caregivers mentioned that their doctor explained FASD to them.

*"Dr. O. was helpful…but I did a lot of learning on my own."*

– Caregiver, Red Deer, AB

*"Doctor who did assessment, explained, as well as D. and M., who were educators and experts."*

– Caregiver, Edmonton, AB

Finally, 9% of the caregivers indicated they had covered FASD in their foster parent or adoption training.

*"Self-research. Some training for adoption training… I've learned about it mostly on my own with some additional training and presentations along the way."*

– Caregiver, Calgary, AB

*"It was covered in our foster parent training but I also attended community workshops and training."*

– Caregiver, Red Deer, AB

## Who explained FASD to your child and how?

51% of the caregivers indicated that they had explained FASD to their family member. While many of the caregivers felt confident and comfortable explaining FASD to their family member, there were many who were clearly not.

*"I've explained it as best I can."*

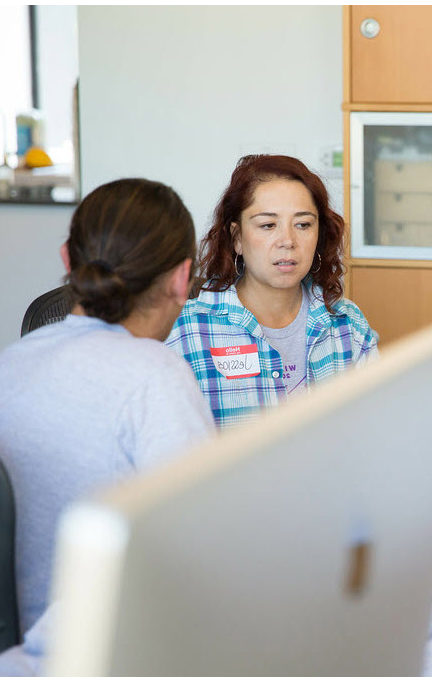
– Caregiver, Millet, AB

*"I have tried to explain it to him."*

– Caregiver, Medicine Hat, AB

*"No, he didn't want to hear about it. He struggled with the stigma… didn't want to be labeled. But no, I send him a lot of information."*

– Caregiver, Edmonton, AB



21% of the caregivers indicated that it was the team of professionals that did the assessment that explained it to their family member. A further 8% of the caregivers indicated that their keyworker from the local FASD Network had explained FASD to their family member. Finally 15% indicated that their family member was still too young to have FASD explained to them.

## What if anything was missing from that explanation?

When the caregivers were asked what if anything was missing from the FASD explanation, 59% of the responses indicated they felt the FASD explanation was rushed, or that the person with FASD did not understand and there was still a lot of unanswered questions.

*"At the time…I think they explained it well but it seemed rushed… we had a lot more questions but not enough time."*

– Caregiver, Red Deer, AB

*"The explanation was rushed, we had unanswered questions."*

– Caregiver, Red Deer, AB

*"Early on, there was not a lot of information, support, content or understanding of FASD…"*

– Caregiver, Calgary, AB

Some caregivers felt a follow-up would have been beneficial to answer ongoing concerns such as behaviour, memory or sensory issues. Some felt the explanation should have included more recommendations for parenting and lifelong care.

*"…what was missing from the assessment was follow up to help with practical information and behavioural information…recommendations. We need to understand assessment information."*

– Caregiver, Edmonton, AB

*"Would have liked more information about how not to become a statistic. How do we remain part of the 30% of FASD that does not end up incarcerated? Autism accounts for only 2% of kids, FASD accounts for over 6% and they get half the funding"*

– Caregiver, Edmonton, AB

# 4.3: Community-Based Services & Supports

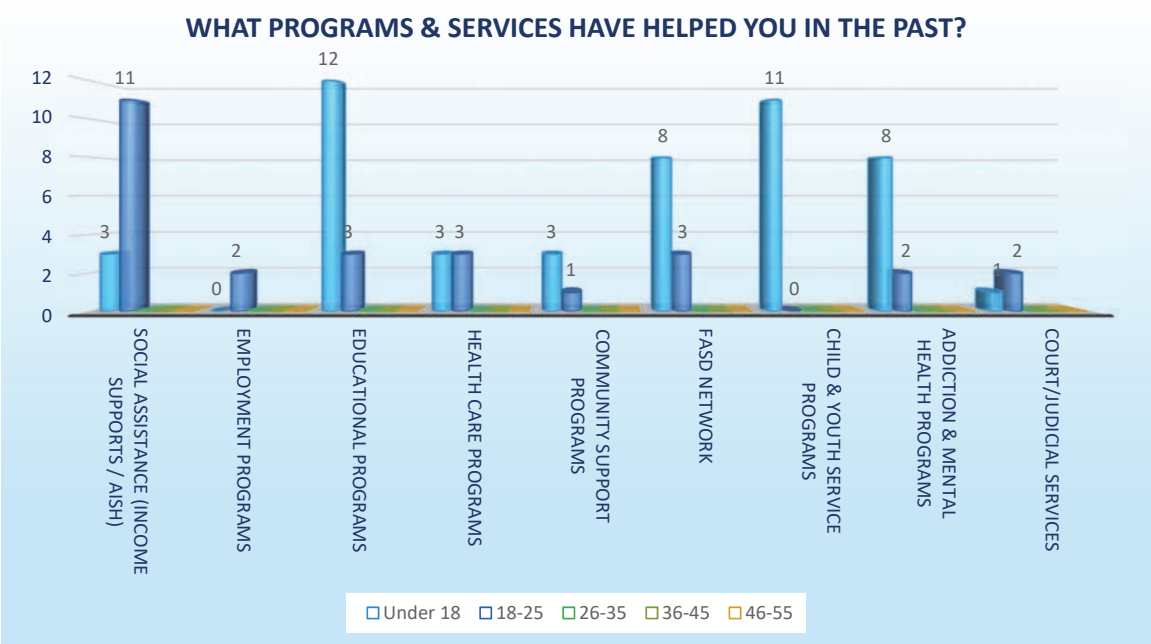
During the caregiver interviews it became abundantly clear that they faced day-to-day challenges with their family members that could only be met with the support of external community-based services and supports. It was imperative we identified which services provided essential supports to their family members and at what age those services became essential.

## What programs and services have helped you in the past?

See chart 4.3.1: When we look at what services the caregivers had accessed with their family member, we see that the majority of the service access occurred in the under 18 category and the 18–25 year old category. It's important to note the vast majority of the caregivers interviewed had family members in these 2 age groups.

Looking at the most commonly accessed services and supports, it's clear to see education related services were the most frequently accessed for family members while they were under 18 years of age, followed by child and youth service programs (which are defined as services and supports available to children or youth in care). The FASD Networks and Addiction and Mental Health services were both accessed by eight caregivers with their family members.

### CHART 4.3.1



## Which service was the most helpful and why?

When asked which service was thought to be the most helpful to their family members, 22% of the caregivers indicated the FASD Networks were the most helpful.

*"The [FASD service provider] has been a huge help. They used to support the school with his education plan. They helped with his resume and potential employers. They also helped me with AISH paperwork and applications."*

– Caregiver, Cold Lake, AB

*"The [FASD service provider] was very supportive early on…when nobody else would."*

– Caregiver, High Level, AB

*"[FASD service provider] is the only services they have received. They have helped me with school meetings to make sure they get the help they need."*

– Caregiver, Fort McMurray, AB

Another 22% of the caregivers indicated that community-based services and supports were the most helpful.

*"[Disability service provider] was most helpful as they support both of us. [FASD Service provider] supports me too."*

– Caregiver, Medicine Hat, AB

*"[Family Service provider] family supports as well as assessment and diagnosis help for parenting/caregivers ongoing help. Otherwise we would have been lost."*

– Caregiver, Lethbridge, AB

A further 20% of the caregivers indicated respite service was the most helpful to them.

*"[Special needs service provider] is a Saturday respite program throughout the school year from 11am–4pm. They have once a month educational support session for caregivers (educational talks, community building, support network etc.). [Special needs service provider] also releases you from the program after 2 years; probably due to lack of funding and resources."*

– Caregiver, Edmonton, AB

*"Respite care is very helpful. [Health service provider] has been very helpful. PDD has been very helpful, so has FSCD."*

– Caregiver, Fort McMurray, AB

*""FSCD…Family Supports for Children With Disabilities…Program Unit Funding (3 years of it) through education. [Special needs service provider] provides respite to parents, they educate caregivers, provide tips for behaviour issues."*

– Caregiver, Edmonton, AB

*"Probably "Supports for Permanency" … provided funding for respite."*

– Caregiver, Edmonton, AB

Finally 10% of the caregivers indicated that gaining access to AISH was the most helpful, with another 10% saying it was the teachers, tutors and teacher aides that were the most helpful.

*"The school has been the most helpful. They have put him in a modified education plan. He is in mainstream classroom with other kids but steps out for SLT (speech language therapist) and certain subjects."*

– Caregiver, Rocky Mountain House, AB

## Which service was the least helpful? And how could those services be improved?

When asked which service was the least helpful, 25% of the caregivers indicated it was Children Services that was the least helpful.

*"The social workers from child and family services did not understand her needs and didn't always provide for her safety in terms of the bio-mother having unsafe and unhealthy access."*

– Caregiver, Red Deer, AB

*"Children services has not been supporting me at all with the children placed in my care. They are still under care of children services until they are 24. Also Dr. M. who does the Psych-Ed Assessments through Children's Services; does assessments but they only say 'shows signs of'... He won't formally diagnose."*

– Caregiver, Kehewin Cree Nation, AB

Another 22% said that community-based organizations were not helpful due to lack of supports and services; relating to income supports, educational supports or parenting supports (respite).

*"AISH worker was not helpful at all… She didn't know anything about FASD or available supports."*

– Caregiver, Edmonton, AB

*"Disability services and children's services… they've cut off the funding for tutors."*

– Caregiver, Red Deer, AB

*"We have been denied respite care through PDD not sure why."*

– Caregiver, Fort McMurray, AB

Another 11% felt services overall were not helpful as there was a lack of awareness about FASD (e.g., ED departments, communities and services)

*"It seems like I am the service. I am the one that advocates for me at the school. I am the one that educates the school staff on FASD, explaining what works and what doesn't with FASD kids. I've had to explain this is a 10 second kid in a 3 second world. You have to respond to their behaviour accordingly; if he acts like an 8 year old you have to punish them like an 8 year old."*

– Caregiver, Fort McMurray, AB

*"All communities and services need more FASD awareness and some staff training."*

– Caregiver, Grimshaw, AB

A further 8% said it was the education system and the schools that was the least helpful when it came to their family member, as they had little to no understanding of FASD.

*"Education. I have had to be a very strong vocal advocate to get him the supports he needed. He would take off all his clothes so he didn't have to go to school and when we did get him to school one of the teachers would have to walk him around the school because he couldn't cope in classroom. He went through 5 schools and he is only in Grade 5...he's also been kicked out of 5 day homes. He's currently at a special needs school."*

– Caregiver, Edmonton, AB

Finally another 8% of the caregiver responses indicated that Addiction and Mental Health services had been unhelpful to their family member.

*"…There were times we've wanted to access Addiction and Mental Health services but he has been told he is not eligible because of his FASD diagnosis."*

– Caregiver, Edmonton, AB

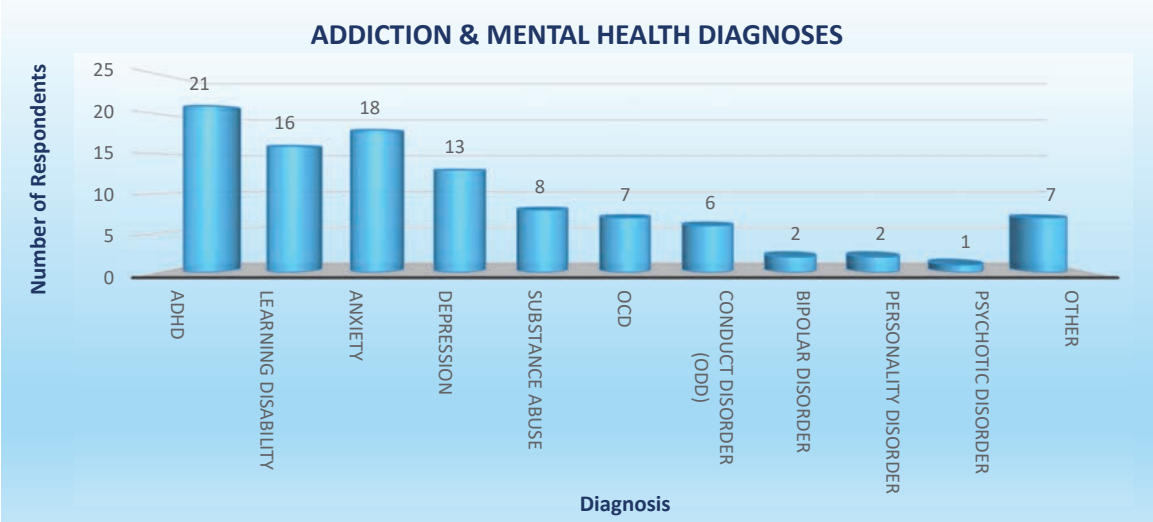
*"Walk-in mental health did our daughter a disservice after she was in hospital. Staff there said she didn't "look" like she had FASD. She got shuffled with previous counselling services. As she got older it was hard to get her into appointments."*

– Caregiver, Edmonton, AB

# 4.4: Addiction & Mental Health Services (AMH)

See chart 4.4.1: Caregivers were asked if their family member had an addiction and or mental health diagnosis. The most common answer was that their family member had been diagnosed with Attention Deficit Hyperactivity Disorder (ADHD). The second most common diagnosis was anxiety, with 18 of the caregivers indicating their family member suffered with anxiety.

## CHART 4.4.1

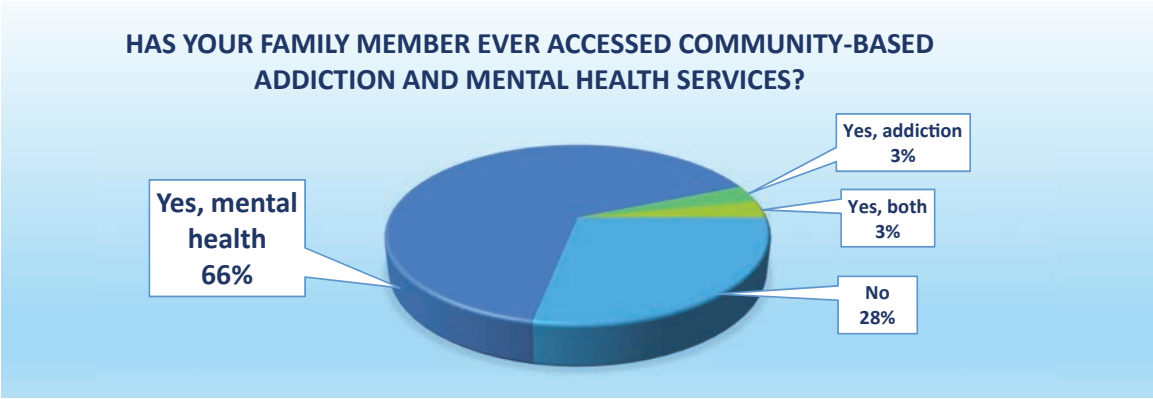



The third most common diagnosis identified by caregivers was a learning disability, with many identifying math, reading and spelling as the primary source of learning difficulty.

## Has your family member ever accessed community-based Addiction and Mental Health services?

See chart 4.4.2: When asked if their family member has ever accessed community-based Addiction and Mental Health services, the caregivers were clear the majority had accessed mental health services (66%), while only 3% had accessed addiction services and 3% had accessed both.

## CHART 4.4.2



Adults with FASD (discussed in Section 5) were asked the same question and it yielded a significantly different responses in terms of service access. Of course it could largely be attributed to age of family members, but when we examined the responses of adult family members and compared their responses to the adults with FASD cohort, there was a stark contrast. This is discussed in greater detail later in the next section.

## What made the services helpful to you?

46% of the caregivers said Addiction and Mental Health services were helpful while 29% felt they were not and 17% were unsure. At 17%, therapy was thought to be helpful by the caregivers, making it the most commonly cited service caregivers thought was helpful. A few of the caregivers indicated the assessment for diagnosis was helpful to allow access to services and ongoing support. One caregiver felt medication was helpful.

*"She had a good therapist who was willing to think outside of the box…she went beyond the prescribed interventions of the day and found what worked for our daughter."*

– Caregiver, Athabasca, AB

*"They were helpful; she struggled with the murder of her father. The wake and funeral was very traumatizing for her. She saw a therapist for it and it was very helpful. She also saw a family therapist with all of us."*

– Caregiver, Red Deer, AB

## How could those services be improved?

When the caregivers were asked how the services could be improved, 29% of the responses indicated Addiction and Mental Health services could be improved with more staff that are FASD-trained.

*"Mental health needs more doctors like Dr. O. that have specialized skills in this area."*

– Caregiver, Edmonton, AB

*"(Staff need) more education about FASD and how it affects brain functioning. More knowledge of effective treatments, techniques and interventions."*

– Caregiver, Medicine Hat, AB

*"We need a lot more mental health services staff that can work with kids with FASD."*

– Caregiver, Grimshaw, AB

A further 21% of the caregiver responses indicated easier access to mental health services and supports was what is needed.

*"These services should be eligible for patients with FASD diagnosis but they're not so they have nowhere to go. There is very limited service availability in rural areas. There are big costs associated that AISH won't cover."*

– Caregiver, Edmonton, AB

*"The waiting list was way too long. I had to advocate for over a year to get her into the service."*

– Caregiver, Edmonton, AB

*"Easier access; the process should be streamlined. I felt like my voice wasn't included as part of the care team."*

– Caregiver, Edmonton, AB

14% of the caregiver responses felt that the services could be improved by listening to the caregivers and the family member in the assessment and treatment planning. A further 14% of the caregiver responses indicated the service could be improved by placing less emphasis on medication, while 11% of the caregivers felt more day-to-day support was needed. Finally 11% of the caregiver responses did not fit in any of the other themes.

*"Maybe better listening; better assessment. Only interested in giving prescription."*

– Caregiver, Red Deer, AB

*"Less emphasis on pills and meds an actually working with the child... listening to the child."*

– Caregiver, Rocky Mountain House, AB

(If yes to addiction services) Have you found staff in community addiction services knowledgeable about FASD? (Yes, knowledgeable; No, not knowledgeable; Somewhat knowledgeable)

Of the 37 caregivers interviewed, 14 caregivers had accessed community-based addiction services with their family member. All 14 caregivers community-based addiction staff were "not knowledgeable."

(If yes to mental health services) Have you found staff in community mental health services knowledgeable about FASD? (Yes, knowledgeable; No, not knowledgeable; Somewhat knowledgeable)

Of the 37 caregivers interviewed, 26 had accessed community-based mental health services with their family member. Of the 26 caregivers, 27% felt mental health staff were "knowledgeable" about FASD and 23% felt the staff were "somewhat knowledgeable" about FASD. 50% felt the mental health staff were "not knowledgeable" about FASD.

## Has your child ever been on an inpatient mental health unit?

Of the 37 caregivers interviewed, 8 caregivers had a family member with FASD who was admitted to an inpatient mental health facility. Three of these caregivers had a family member who was admitted between 2 and 5 times.

## Has your child ever been in a residential treatment facility for substance abuse?

Of the 37 caregivers interviewed, only 2 had a family member with FASD who was admitted to an inpatient addiction treatment centre.

## What made those inpatient services helpful to you?

Of the 10 caregivers who had a family member spend time in an inpatient mental health facility or an inpatient addiction treatment facility, there were only 2 responses to how the inpatient services were helpful, the responses are as follows:

*"Yes. He was in crisis becoming very threatening and not taking medicines. So yes. It did avert a crisis situation."*

– Caregiver, Edmonton, AB

*"They kept her clean and safe from drugs."*

– Caregiver, Edmonton, AB

## How could those services be improved?

Of the same 10 caregivers, there were only 2 themes pertaining to service improvement of those services. One was that the caregivers would have liked to see more staff and services that dealt specifically with FASD. The second theme was that they would have liked to see more effective transition planning out of inpatient care.

*"While inpatient, there was no services that looked at his needs specifically. No programming that considered his needs as a person with FASD."*

– Caregiver, Edmonton, AB

*"When she was in addiction treatment they did not understand persons with FASD. All they were really able to do was to keep her clean but she did not understand a lot of the steps. There was also no transition plan for FASD clients (housing)."*

– Caregiver, Edmonton, AB

There was one response to this question (below) that echoed many comments made by other participants in separate interviews. These were typically comments made outside of the interview template and were not recorded.

*"If someone has brain damage; they don't have the capacity to stop drinking or doing drugs on their own...so at what point will they ever get mental health services?*

*Because mental health services doesn't help people who are using drugs and alcohol."*

– Caregiver, Millet, AB

(If yes to inpatient or residential treatment) Have you found inpatient staff knowledgeable about FASD? (Yes, knowledgeable; No, not knowledgeable; Somewhat knowledgeable)

Of the 10 caregivers who had a family member spend time in an inpatient mental health facility or an inpatient addiction treatment facility, none felt inpatient staff were "knowledgeable."

# 4.5: Health Services & Supports

## Does your child or family member take medication?

Of the 37 caregivers interviewed, 21 had a family member who was taking medication to treat health issues thought to be related to their FASD diagnosis. While caregivers were not asked which specific medications their family member was taking or which ailments they were currently treating, the majority indicated the medication was to treat ADHD-related symptoms.

## Does the medication help and does he/she ever experience adverse side effects?

Of the caregivers who had a family member currently taking medication, 52% felt that the medication helped their family member, 35% were unsure if it helped their family member and 13% said it did not help their family member. The most common side effects reported by caregivers were poor sleep patterns and loss of appetite.

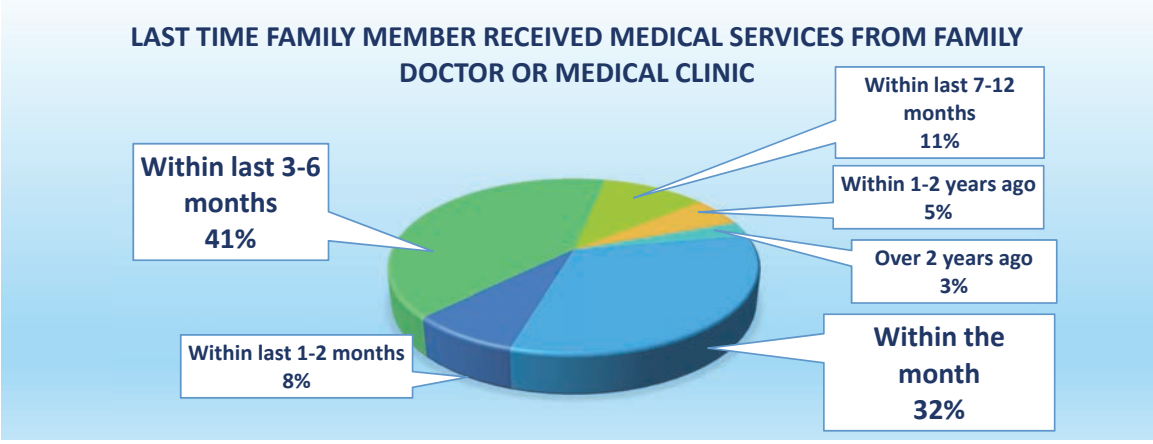
## Does your child or family member have a family doctor?

The majority of the caregivers (84%) indicated their family member had a family doctor, while only 16% indicated they accessed healthcare via walk-in clinics, primary care networks or other.

## When did your child or family member last receive health services from his/her family doctor or a medical clinic?

See chart 4.5.1: The majority of the caregivers (82%) indicated their family member had accessed health services from their chosen service provider in the previous 6 months, with 32% of them having seen the doctor in the past month.

### CHART 4.5.1



### Have you found doctors to be knowledgeable about FASD?

See chart 4.5.2: While many of the caregivers spoke of well-established and trusting relationships with their doctor, the majority (55%) indicated they did not feel he or she was knowledgeable about FASD.

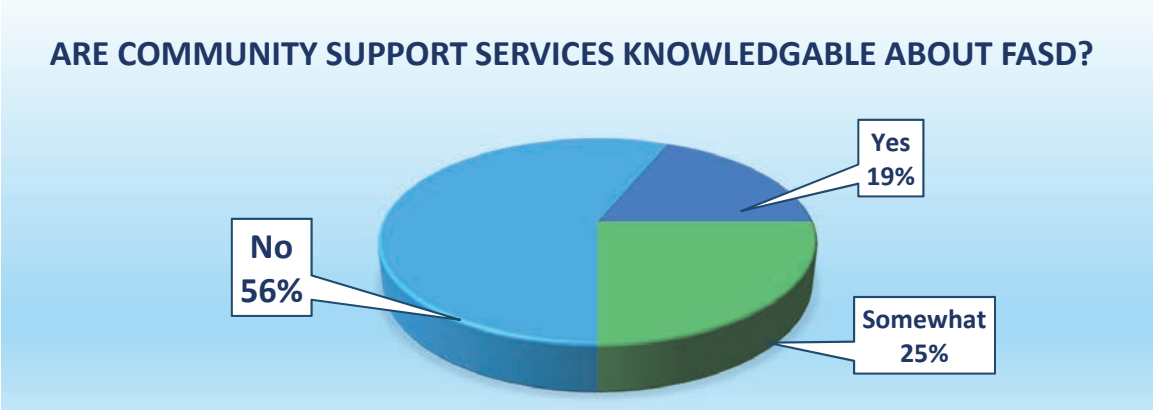
**CHART 4.5.2**

## 4.6: Community Awareness

### Have you found support services in the community (not Addiction & Mental Health services) to be knowledgeable about FASD?

See chart 4.6.1: While 19% of the caregivers felt community-based services and supports were knowledgeable about FASD, 56% of them felt they were not knowledgeable about FASD. Still, 25% felt community-based services were somewhat knowledgeable about FASD.

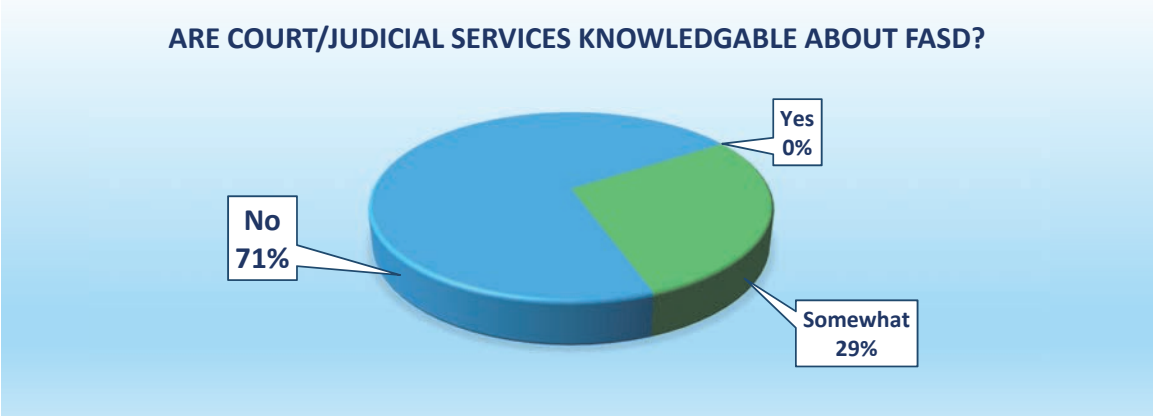
**CHART 4.6.1**



## Have you found court/judicial services to be knowledgeable about FASD?

See chart 4.6.2: While only 14 of the caregivers had a family member who was an adult, 8 had previous involvement with courts and judicial services. Of that 8, 71% felt courts were not knowledgeable about FASD while 29% felt they were somewhat knowledgeable. None of the caregivers felt the courts or judicial services were knowledgeable about FASD.

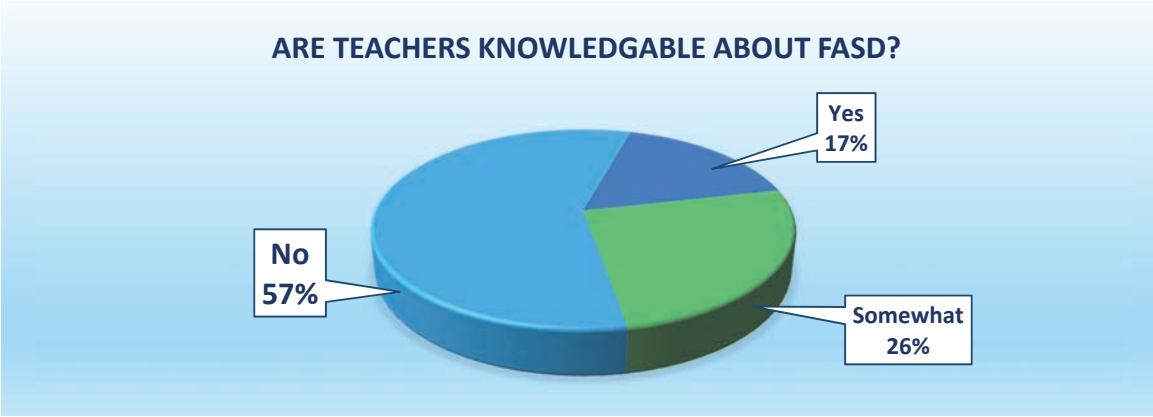
### CHART 4.6.2




## Have you found teachers to be knowledgeable about FASD?

See chart 4.6.3: The majority (57%) of the caregivers felt that teachers were not knowledgeable about FASD. There were a few interviews in which the caregivers felt highly supported by the local school and felt the teachers were quite knowledgeable about FASD, but these cases were rare. 26% of the caregivers felt the teachers they worked with were somewhat knowledgeable about FASD.

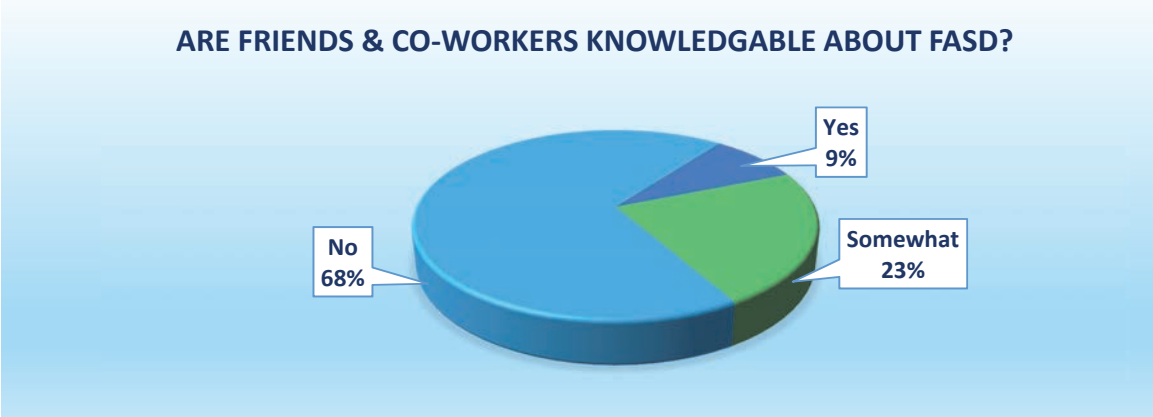
### CHART 4.6.3



## Have you found friends and co-workers to be knowledgeable about FASD?

See chart 4.6.4: When asked about the FASD knowledge of friends and co-workers, most of the caregivers (68%) felt their friends and co-workers were not knowledgeable about FASD, while 23% felt they were somewhat knowledgeable. 9% of the caregivers felt their friends and co-workers were knowledgeable about FASD but cited clear reasons for that knowledge (i.e. they worked with special needs, had special needs children, were also foster parents etc.).

### CHART 4.6.4

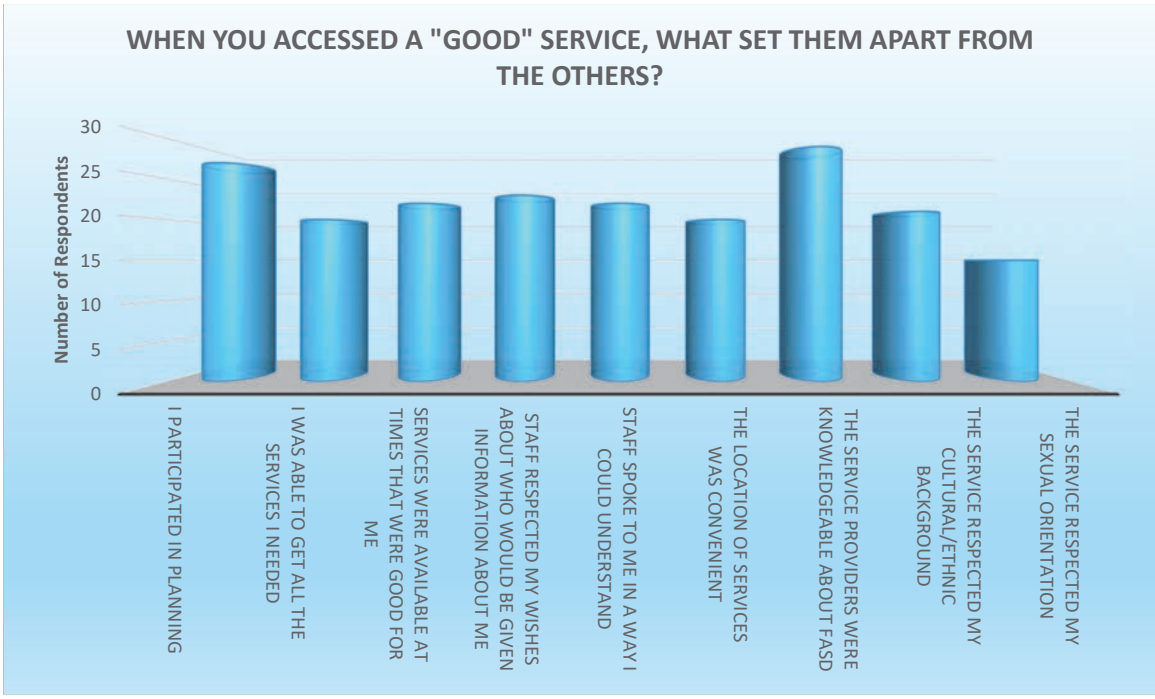


# 4.7: Care Planning

## When thinking about the good services and supports that you accessed related to your child's FASD, what set them apart from the others?

See chart 4.7.1: It was clear the caregivers felt the presence of knowledgeable service providers was the most important characteristic when assigning value to a service or support. The second most important characteristic was a service that facilitated the caregiver's inclusion in the care planning process. Finally, the caregivers felt it was important that the service acknowledged and respected their confidentiality.

**CHART 4.7.1**




## How have you been involved in decision-making about your child's care?

When caregivers were asked about their involvement in their family member's care planning, 43% felt they were leading the care plan and were the primary decision maker. A further 34% of the caregivers felt they were partially involved in the care planning while 23% felt they were very involved in the care planning.

*"I have led his decision making and care and if I hadn't he wouldn't have gotten any care. This is why we need to be listened to and respected by the medical community."*

– Caregiver, Edmonton, AB

*"I'm more often the leader of the plan. I seek them out. I see what services they can provide."*

– Caregiver, Cold Lake, AB

Many of the caregivers mentioned the need to be strong advocates to ensure their family member received the services he or she required.

*"Teachers were always reluctant to meet with us to discuss her academic process, so we had to be very vocal regarding her needs. We have had to be real advocates for her education."*

– Caregiver, Red Deer, AB

*"We were strong advocates for our daughter's care and we had to lead her planning or else nobody would have."*

– Caregiver, Athabasca, AB

## 4.8: Barriers & Challenges

### Tell me about the barriers and challenges that you and your child have experienced at transition points in his/her life?

When asked about barriers and challenges at transition points, the most common answer among the caregivers was challenges with education. In fact 31% of the caregivers indicated they had difficulty with transition points in school, limited FASD awareness among teaching staff or limited access to necessary educational supports.

*"Transition from pre-school to elementary was a very difficult transition. The school is not always receptive to caregiver concern about education plans or is ill-equipped to accommodate them. We have had to fight for tutors and non-inclusive classrooms. Often the supports we do get are self-funded. We have self-funded her educational psychology assessment and subsequent tutors."*

– Caregiver, Edmonton, AB

*"PUF program which is for disabilities wanted to bump her up to Kindergarten. I didn't want her to go to Kindergarten, but allowed them to. At the end of Grade 1 she didn't know her alphabet yet so we held her back another year."*

– Caregiver, Grande Prairie, AB

*"Had some difficult transitions in school; falling behind in grades with moving around in foster care. A lot of challenges with teachers not wanting to hold her back in grade 1. She had a lot of anxiety about moving to middle school."*

– Caregiver, Red Deer, AB

*"Every transition for my son is difficult, even moving-one classroom to another. Every year I have to go in and meet the teachers to explain FASD and how to work with FASD kids."*

– Caregiver, Fort McMurray, AB

Another 19% of the caregivers indicated that their family member had difficulties with mental health as their family member grew through the different stages of development.

*"She was very emotional and defiant as a teenager. She had an adult body but her mind was still very much like a child. I had a lot of support from my parents. I was able to get some respite care."*

– Caregiver, Edmonton, AB

*"About a year and a half ago, at age 8 or 9 we had a particularly more angry… struggling period. We were constantly reinforcing messages that we cared for him…we set boundaries…understanding FASD brains and processing."*

– Caregiver, Edmonton, AB

Another 19% of the caregivers indicated that it was the barriers to services and supports that were the most challenging part of transitions.

*"I had zero assistance with J's transition; from [Family service provider] or the [Health service provider]. The support service before T. was not as helpful as T. is now. There are so many things about transition I didn't know… things like AISH, I would have to figure out on my own."*

– Caregiver, Kehewin Cree Nation, AB

*"(We had to) advocate and fight for things all the way along. Some services are unaware…some staff are unaware and don't know what things (services) can be accessed."*

– Caregiver, Edmonton, AB

*"I applied for respite care and was unable to get it because he was too young for an assessment. This was a huge factor contributing to burn out. Accessing childcare for him was a challenge because there are no childcare centres and the centres that are available know nothing about FASD. This made it difficult for me to go to work."*

– Caregiver, High Level, AB

# 4.9: Opportunities for Service Enhancement

## What things are hard for you and your child to manage and what would help you and your child manage home and community better?

There was a wide variety in the ages of the family members with FASD, so there were a number of different challenges that the caregivers faced on a daily basis. In younger family members, things like getting out of bed and getting ready for school were extremely difficult. In teenage family members, being bullied at school or making poor choices were frequent concerns. Common to all caregivers, was the concern that their family member was too trusting and vulnerable to exploitation or abuse.

In identifying what might be helpful in terms of support services, 57% of the caregivers indicated that more support services were needed. When pressed for a definition of support services most caregivers described a caseworker or key worker type role that would support the caregiver and the family member with day-to-day challenges and problem solving.

*"People with FASD need access to someone who helps them. We need an FASD support service that supports people with FASD. We get some support though PDD and it is a life saver but a lot of people don't even get that. They need actual people that support them and have a relationship with them…"*

– Caregiver, Edmonton, AB

*"Having access to more people who understand FASD needs. For example, respite and support people who get these kids."*

– Caregiver, Edmonton, AB

*"(Need) people who he is attached to … to stay and fight for him and advocate for him…it's a big strength in how to keep him safe and alive."*

– Caregiver, Cold Lake, AB

A further 46% of the caregivers indicated that what they needed most was a mentor for their family member. Someone who could support their family member's needs for social interaction in a safe, positive and healthy manner. The caregivers tended to see the mentor as someone who could model good behaviour, reinforce healthy living and support them with setting and achieving goals.

*"It would have helped to have a mentor to spend time with her so she was having the same message from someone other than us...to support her with the uncertainty."*

– Caregiver, Athabasca, AB

*"Waking up at a reasonable hour. She really struggles with personal hygiene. She really struggles with housekeeping, cooking and laundry. She can't manage any finances. She needs help with all life skills and needs constant reminders… she loses keys and gets locked out of her apartment."*

– Caregiver, Edmonton, AB

Many of the caregivers were adamant better educational services and supports were needed in school. 24% indicated that better access to mental health services were needed in school. Some of the caregivers indicated better support with learning disabilities, better educational strategies and better planning were also needed.

*"She is very trusting and makes poor choices. She really struggled in school but was always in mainstream classes."*

– Caregiver, Red Deer, AB

*"Maybe more educational help for kids. Maybe more teaching and learning about my own FASD."*

– Caregiver, Fort McMurray, AB

The caregivers emphasized the importance of respite care. 19% of the caregivers indicated that respite care was an essential resource that should be accessible to all families with an FASD family member. Family members with FASD can put a lot of strain on families, with challenging behaviour or day-to-day struggles. This puts caregivers under a lot of stress and respite care is often the only resource that provides temporary relief from that stress.

*"We need more respite. He got respite from age 7 to 9…as every kid gets 2 years. He would be eligible for more respite at age 14 if he had low IQ but he doesn't. If you ask any caregivers with an FASD kid, respite is an absolute lifesaver and we need more of it."*

– Caregiver, Edmonton, AB

Many of the caregivers indicated that the access criteria of many services or supports was what needed to change if caregivers are to feel supported. 16% of the caregivers commented on how their family member was deemed ineligible for services and supports because he or she did not meet the access criteria, even when there was a clearly demonstrated inability to cope without the service.

*"Access should depend on level of functioning or presenting need. If you need help. You need it. It should not have to reach a crisis point to get help."*

– Caregiver, Red Deer, AB

The caregivers were very concerned about their family members' inability to manage money. 14% of the caregivers indicated a service or support was needed that could support their family member to manage money more responsibly.

*"I worry about who will help him manage his finances and responsibilities when I am gone. There is no services that provide support in these areas like money management."*

– Caregiver, Edmonton, AB

Finally the caregivers indicated a more robust continuum of care was needed, with better interagency planning. 11% of the caregivers indicated that input was needed from multiple services and that it should be coordinated jointly to avoid people falling through the cracks.

*"We need more respite care that lasts more than 2 years. We need a consistent continuum of care like Calgary. Calgary has a continuum of care that follows the child to adulthood. Calgary has a system that provides caregiver supports, education supports, health supports, assessment diagnosis clinics; that all lead to better outcomes for persons with FASD in Calgary as opposed to Edmonton. This was demonstrated in a study done by [Policy service provider]."*

– Caregiver, Edmonton, AB

*"If child & family services, healthcare and education had a joint plan for kids with FASD. There should be one table where someone from each sector is there to ensure those needs are met. It would also be awesome if we had dedicated FASD support services in the community similar to the autism centre."*

– Caregiver, Edmonton, AB

## Tell me about your child's goals and dreams in life

As previously stated, the family members of the caregivers were all different ages, ranging from small children to adults. As one might expect, there was a wide variety in terms of what goals and dreams the family members have.

According to the caregivers, the younger children tended to have career aspirations to be things like a policeman or an astronaut. In the middle-aged children there tended to be more interest in animals and computers. In the later teens and young adults the focus was more on independence, with goals like finishing school, moving out and starting a family.

*"She wants to be an astronaut. I would like to see her finish school and live on her own but it may not be possible. She could work but it would need supported employment."*

– Caregiver, Edmonton, AB

*"He loves science and nature programs. He loves working with his hands and building things. He wants to be a police officer."*

– Caregiver, Grimshaw, AB

It was interesting to find that a high number of the caregivers described their family member as being really drawn to the arts. In fact, 30% of the caregivers indicated their family member was involved in art and or music.

*"He loves singing and music. He is good with video games and computers. I would like him to work in some kind of job involved in music."*

– Caregiver, Lacombe, AB

*"A musician…he has been in a band… wants to be rock star! He has a soft spot for homeless individuals more easily because of his parents etc. Resiliency… he really connects with other adults and youth. He loves animals, connects with family pets. He wants to live on his own, have a job, etc."*

– Caregiver, Calgary, AB

Equally intriguing, was the number of family members with FASD who were identified as working really well with animals. In fact, 19% of the caregivers described their family member as working really well with animals.

*"She's really good with animals. She is a very happy and kind child. She wants to be an animal trainer."*

– Caregiver, Grande Prairie, AB

*"She wants to travel and have fun. She is really good with animals. She loves music and singing."*

– Caregiver, Edmonton, AB

Similarly, a good portion of the family members were known for working well with children. In fact, 16% of them were described as working really well with younger children. Furthermore, some were actually in the process of pursuing a career in early childhood education or were training to be an educational assistant.

*"He wants to finish college with an educational assistant certificate. He wants to move out on his own but he is not quite ready in my opinion."*

– Caregiver, Cold Lake, AB

*"He is very smart. He reads a lot, has hundreds of books. He can learn new things but needs one-on-one support. He is currently starting early childhood development at [Education service provider]. He is also in a diploma program to be an educational assistant."*

– Caregiver, Red Deer, AB

## What services could be put in place to help your child achieve his/her goals and dreams in life?

When the caregivers were asked what services would best support the goals of their family members, the majority (33%) indicated that their family member would need a long term support service. The support service would need to provide a long term caseworker who would review their needs and coordinate appropriate services to ensure those needs were met. The needs were described as being related to health, housing, finances and other support services.

*"I think more support during her teenager years. I know from other foster children I have cared for that their teen years will be the most challenging so I would need more help and support then…educational, mental health …"*

– Caregiver, Red Deer, AB

*"From age 16 on…should prepare for transition to adulthood. Individuals won't receive as many services & supports when older. Additional funding supports for adults…for transition to work… programs are needed that are consistent, meaningful."*

– Caregiver, Red Deer, AB

*"(He) has worked with the PCAP program… people with FASD need intensive involvement…need to help figure out personal stuff like prevention & birth control. For FASD, needs are life areas, life skills, stabilization, ongoing lifetime support, financial help, housing stability."*

– Caregiver, Edmonton, AB

The caregivers indicated that a mentor would be needed to ensure the family member's day-to-day needs were met. 23% of the caregiver responses felt their family member would need to have a mentor in place that provided daily one-on-one support. The caregivers were fairly consistent in their responses that independent living would only be possible if there was a support person on hand to support their family member with day-to-day things like personal hygiene, housekeeping, buying groceries and paying bills. The mentor would also play a vital role in meeting the family member's needs for socialization and interaction, as many family members are reclusive or have difficulty leaving their comfort zone.

*"He needs a career counsellor to do an assessment of what he can do and be good at. He needs to be reassessed for his medication. He needs to be connected to a mental health counsellor. He needs a mentor to get him out and socializing and getting to his appointments."*

– Caregiver, Fort McMurray, AB

*"She'd need a one-on-one support worker to help her with getting up, reminders, on-the-job supports and reminders to keep on task."*

– Caregiver, Kehewin Cree Nation, AB

*"He could use a support worker; someone outside of the family. He needs to be moving towards independence as we are getting old and will not be around. It would be helpful for him to socialize with someone other than us parents, someone to help him move out of isolation."*

– Caregiver, Red Deer, AB

Finally, the caregivers were clear that special education and training would need to be put in place if goals of the family members were to be achieved. 19% of the caregiver responses indicated that modified educational programs or training would need to be in place along with appropriate educational supports.

*"Specialized education and supports. Lifelong support with a continuum of care like Calgary. Caregiver supports, both educational and social."*

– Caregiver, Edmonton, AB

*"She might benefit from a modified educational program that could help her to be a social worker but also special training for her teaching staff so they could help her with motivation. She also needs childcare services and supports to be successful and this is very limited in the community in terms availability."*

– Caregiver, Red Deer, AB

*"She was all set to go to [Education service provider]…a place where they teach people with special needs basic life skills. I think the funding was cut because she never got to go. It would have been great for her. They go for a whole school term… work with animals and the outdoors."*

– Caregiver, Edmonton, AB

## What advice would you give to service providers in caring for and working with individuals with FASD and their families?

As one might expect, the caregivers were very passionate and enthusiastic about sharing their advice for service providers. By far, the most common advice to service providers was to have more FASD education and training available to staff. 27% of the caregivers indicated that service providers needed to better understand FASD as a brain injury and a brain disability.

*"There must be in-depth education about FASD and its ramifications…cognitive and emotional limitations. More education would make a big difference…"*

– Caregiver, High Level, AB

*"People working with persons with FASD need more education and training. Training should not be once a year but once a month."*

– Caregiver, High Level, AB

*"They need to be moving beyond FASD 101…needs to be ongoing training. Just because you know someone with FASD that only means you know one person. They're on a spectrum…need to be open to awareness."*

– Caregiver, Calgary, AB

The caregivers were also passionate about encouraging service providers to "think outside the box" when planning intervention or service delivery with a family. 21% of the caregivers indicated that services needed to be flexible and service providers must be open minded when planning service delivery with a family, emphasizing it was a spectrum disorder and no two cases were the same.

*"To think outside the box. Every one of these people is different and what works for one client may not work for the next. I think FASD education and training is so limited because every person with FASD is so different. Our son needed a picture of shoes taped to the wall to know where his shoes went. This did not work with his sister. She needed the word "shoes" taped to the wall."*

– Caregiver, Athabasca, AB

*"Always use Trauma Informed Care. Think outside the box when problem solving. Use more positive reinforcement when working with persons with FASD. They don't understand consequences. The kids with FASD need support before they get into trouble and after. They need to be taught a new skill and be put on a new path. We need to look at prevention instead of crisis response."*

– Caregiver, Edmonton, AB

*"You need to be consistent; don't give up on people. You need to think outside the box to support people with FASD; you need to "work the system" to get their needs met. You need to be a strong advocate to get their needs met."*

– Caregiver, Red Deer, AB

13% of the caregivers emphasized the need for service providers to be patient and understanding when communicating with persons with FASD.

*''Services need to be more flexible and accommodating. FASD services cannot be one-size-fits-all. We need more services that are patient and understanding… services that apply their services based on his or her level of understanding."*

– Caregiver, Edmonton, AB

*"Don't assume you understand, ask for clarification. Ensure communication is understood. Come up with strategies for effective communication. Routine is important, deviations from the norm are met with struggles."*

– Caregiver, Red Deer, AB

*"They need to be patient and understanding with people with FASD. They need to listen to the family members because they know the most…they know what has been tried, what works and what doesn't."*

– Caregiver, Fort McMurray, AB

12% of the caregivers indicated that service delivery could be improved simply by listening to families more.

*"Don't disregard or discount the role of families. Families and caregivers really know their child. Due to being on a spectrum…need to know the history and prepare… need to know about how behaviours look and what they mean. Behaviour has context. Some families don't see disability, get stuck when outcome is different due to thinking child will have different level of success."*

– Caregiver, Calgary, AB

*"It's really important that they listen to the family members as they are the ones that live with the child. The child's perception is not always accurate or realistic."*

– Caregiver, Red Deer, AB

Finally, 12% of the caregivers indicated services needed to be more consistent with established structures and routines.

*"FASD is a hidden disability. Can't take behaviours personally. Highly structured and consistent environments with swift consequences. They do not understand long term consequences. You need to respond in a way that works for them."*

– Caregiver, Grimshaw, AB

*"Be patient with FASD clients. Look at the disorder itself; understand the brain disability. Consistency and repetition with a lot of things. Be adaptable and understanding of behaviour. Expect the unexpected."*

– Caregiver, Medicine Hat, AB

## Is there anything you would like to add that has not yet been discussed?

Given the complexity of FASD and the many ways it affects families, this question was included in the interview template to give the Caregivers an opportunity to discuss concerns they had that were not discussed elsewhere in the interview. In that the question is completely open-ended, there were few answers of consensus. There were however, closely related themes that spoke to a larger issue. One such issue was FASD awareness.

Many of the caregivers saw a need for more FASD awareness in their community, citing public awareness as the only means of stopping the shame and stigma often associated with FASD.

*"I think more resource needs to go into public awareness so we can get rid of stigma…"*

– Caregiver, Edmonton, AB

*"We have to stop the shame and stigma that comes with the term 'FASD. Service providers and service awareness campaigns need to use more understanding and compassionate language...staff everywhere should be trained in FASD awareness. That awareness (training) should always include lived experience."*

– Caregiver, Edmonton, AB

Continuing on the issue of awareness, many of the caregivers felt specific public service providers needed more education and training regarding FASD. Teachers in the education system were also mentioned frequently.

*"We need the schools committed to learning about FASD; to training their staff and giving them access to these opportunities."*

– Caregiver, Fort McMurray, AB

*"We need to see more commitment from the schools in terms of learning about FASD. They might be struggling with a number of students because they wouldn't recognize the signs or traits of FASD."*

– Caregiver, Fort McMurray, AB

*"The education system needs a lot more professional development that looked at FASD and strategies to educate them."*

– Caregiver, Edmonton, AB

*"Quite often my son would do well in a small quiet classroom with one teacher per four kids and every time he would start to be successful in this environment they would try moving him to a regular classroom full of kids...ignoring the fact he was successful because of the environment."*

– Caregiver, Edmonton, AB

One caregiver felt strongly that greater FASD awareness was needed in primary care.

*"Medical transition… There's a need for transitional supports when kids with FASD move to adulthood. Need doctors who are aware of complications like long-term medical issues…being predisposed to other diseases and early onset stuff. There is some arrogance with medical docs and specialists, they need to understand adult FASD patients."*

– Caregiver, Calgary, AB

One caregiver felt the police needed greater FASD awareness in the community.

*"The police services after our daughter's assault…were not very understanding. We felt dropped after the incident. (They) could use some help with understanding FASD…understanding the victimization relating to our daughter."*

– Caregiver, Didsbury, AB

One caregiver felt the Addiction and Mental Health services needed greater FASD awareness.

*"Addiction and Mental Health services and workers…their staff need to understand behaviours and different presentations of people in treatment. They (person with FASD) might not make progress in the same way. So they need to change expectations."*

– Caregiver, Edmonton, AB

Many of the caregivers raised concerns about barriers to accessing services. The PDD access criteria that uses IQ scores was mentioned specifically as a barrier to service access.

*"(Some of) the services base involvement or access on IQ numbers instead of actual ability to function."*

– Caregiver, Edmonton, AB

*"(The) PDD gap with IQ criteria access… is very frustrating…but also no support with transition to adult services. These kids need a lot of support funding, they can't manage money, and sometimes they're better off with none at all."*

– Caregiver, Calgary, AB

*"…PDD has supported employment programs where the government pays wages, but FASD are not eligible. It's all based on IQ which is misleading because someone may have an IQ over the baseline but can't function independently with basic day-to-day living. This means they get no help with housing, employment and training or even day-to-day support people."*

– Caregiver, Medicine Hat, AB

Many of the caregivers identified the delays of FASD assessment and diagnosis as a barrier to service access.

*"The kids with FASD need better access to faster diagnosis and the diagnosis should have dedicated resources attached to them."*

– Caregiver, Didsbury, AB

*"There is a lot of confusion about FASD assessments…and a lot of inconsistencies about how to get one. Why is it so confusing? Why is it so difficult? Particularly for children under twelve in Red Deer?*

– Caregiver, Red Deer, AB

*"There is a huge population out there that have FASD that has been in and out of jail…that have never been assessed and never received services. Or they have been assessed while in children's' services but nobody told them. Our child's four brothers have FASD diagnoses and only a few of them receive supports…the others are in and out of jail and struggle with homelessness."*

– Caregiver, Edmonton, AB

Many of the caregivers had concerns about the transition to adulthood, and how it might mean a barrier to service access.

*"FASD effects…the damage is permanent…a lifetime challenge. Services can't walk away at adulthood, they still need supports. If supports don't continue, it's not reflective of the earlier supports with childhood. Need continuity as to not waste the services that happened earlier."*

– Caregiver, Calgary, AB

*"Transition point from teen to adulthood was done without any planning."*

– Caregiver, Red Deer, AB

Many of the caregivers indicated that the barriers to service access were so high that a high level of advocacy was needed to get support with their family member's needs.

*"We would not have any services without [Advocacy service provider] advocating for PDD supports. Without PDD supports I don't know what we do. There is this common misconception. There are a lot of services and supports for FASD and there is not. There is nothing."*

– Caregiver, Edmonton, AB

*"She is only successful today because of the support and advocacy of us and the community."*

– Caregiver, Red Deer, AB

*"There should be a children's advocate that can support caregivers who are not strong advocates. An office that can contact education and ensure the child's needs are being met."*

– Caregiver, Edmonton, AB

The caregivers expressed needs for services that were not currently available. Some caregivers indicated that a service was needed to provide adults with FASD day-to-day independent living support.

*"There needs to be some kind of service that supports persons with FASD with day-to-day living. They forget housekeeping and managing a household."*

– Caregiver, Red Deer, AB

*"There has previously been a lot of supports and services available. There needs to be programming for persons with FASD; to support them with housing, supported employment, day-to-day living supports, services navigation, mentoring."*

– Caregiver, Red Deer, AB

One caregiver indicated service dogs were not available but would be a huge support.

*"I would love to see her get access to a service dog. This would be a huge help in terms of meeting and making friends. As she really struggles to make friends. The [FASD service provider] has been a huge help and very supportive. I rely on them heavily to support me with other professionals."*

– Caregiver, Grande Prairie, AB

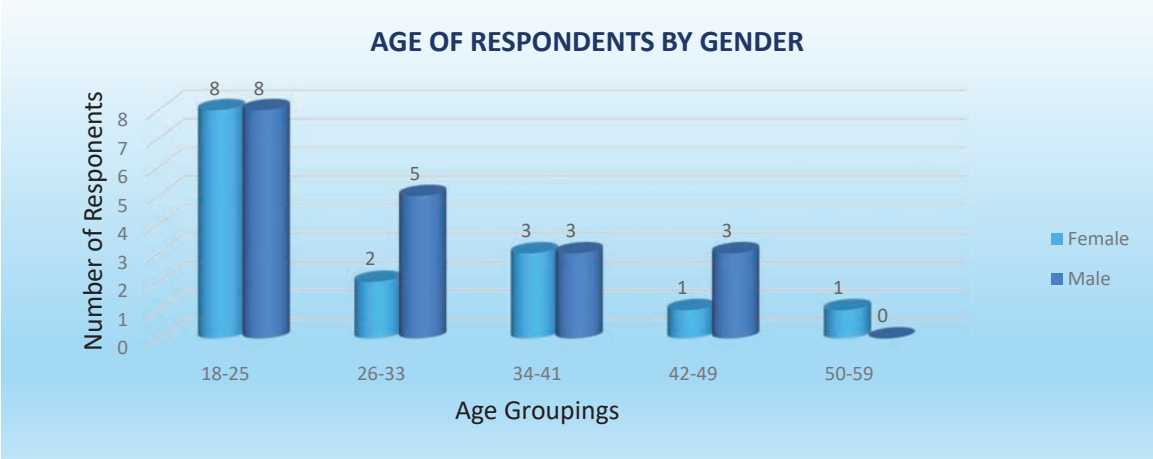
# Section 5: Perspectives – Persons with FASD

Listening to the perspectives of service providers can provide useful insight into how services could be improved to better support service providers as well as persons with FASD. Listening to caregivers can provide useful insight into how services can be improved to better support caregivers as well as persons with FASD. But only through listening to persons with FASD can you capture the firsthand insight into how services can be improved to better support them.

## 5.1: Demographics

See chart 5.1.1: The project had a total of 37 participants that identified as having FASD. The majority of these participants were contacted and recruited for this study through the FASD Networks throughout the province and providers who deliver services to persons with FASD.

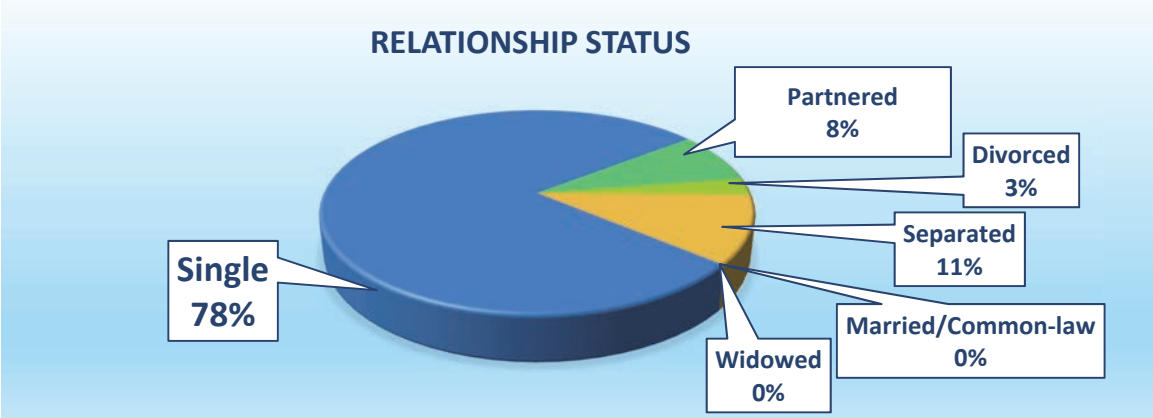
### CHART 5.1.1




See chart 5.1.2: The vast majority of the persons with FASD identified themselves as single, separated or divorced (92%). This speaks volumes to the relationship challenges present when someone has FASD.

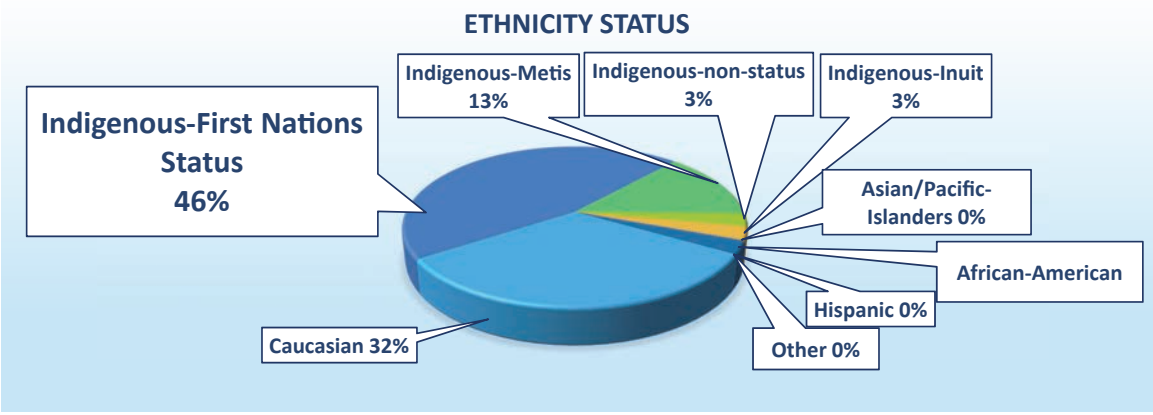
A number of the persons with FASD described multiple broken relationships that were marred in dysfunctional or abusive behaviour. Substance abuse was frequently mentioned as a contributing factor to these relationship breakdowns.

## CHART 5.1.2



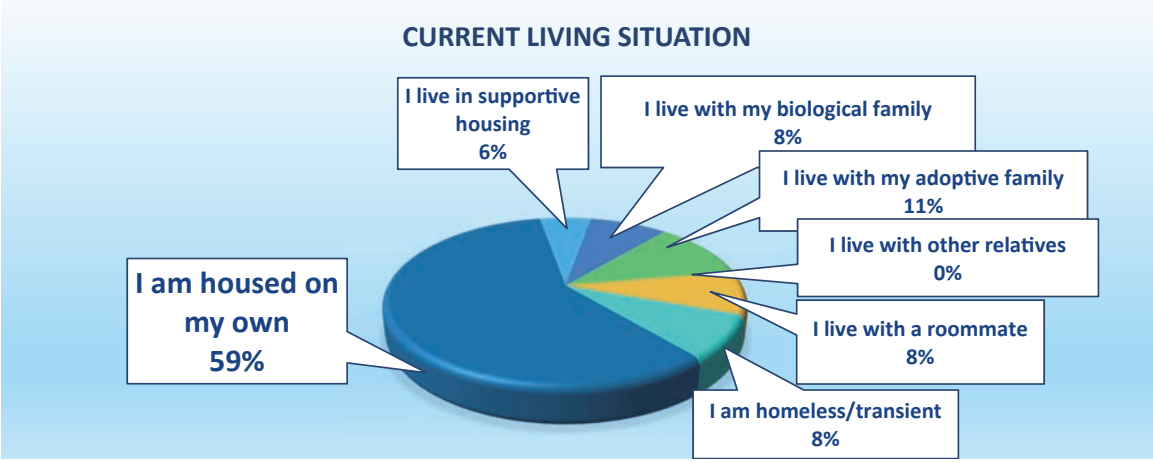

See Chart 5.1.3: The majority of the persons with FASD were status First Nations (46%) but when we add Non-Status First Nations, Metis and Inuit, we see that 65% of the participants identified as Indigenous. A further 32% of the participants identified as Caucasian, with the balance being comprised of African American.

## CHART 5.1.3



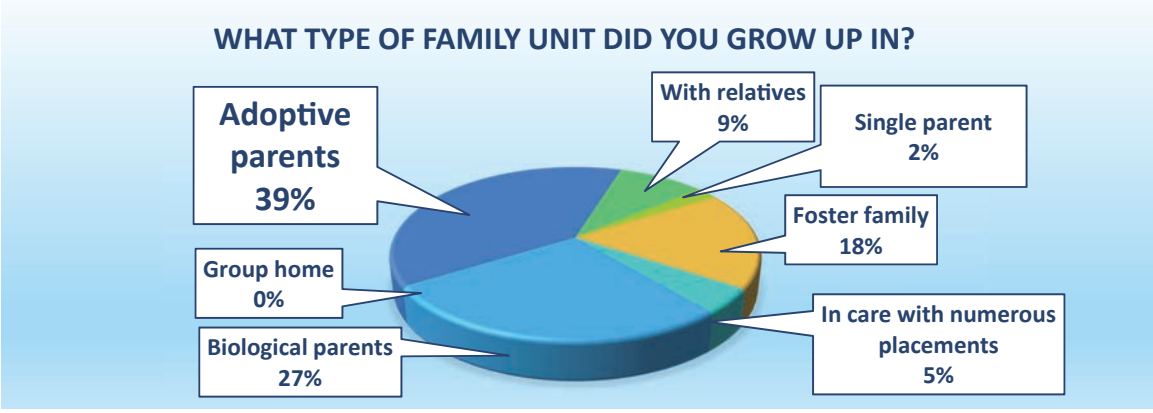
See chart 5.1.4: There was a wide range of responses when it came to the current living situation of persons with FASD. While 59% of them lived on their own, the balance was spread between a number of other categories. It is worth pointing out only 6% of the persons with FASD were currently living in supported housing and 8% identified as being homeless or transient.

## CHART 5.1.4




See chart 5.1.5: When asked what type of family unit participants grew up in, the majority responded with either adoptive parents (39%) or biological parents (27%). When we add adoptive parents, to relatives, foster families and numerous placements we see that 71% left the care of their biological parents at a young age.

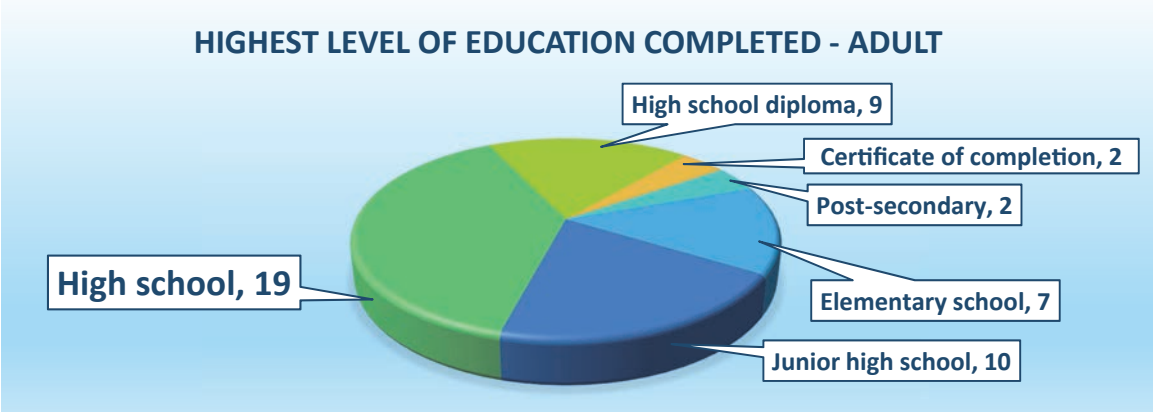
## CHART 5.1.5




See Chart 5.1.6: When we look at education, we see many of the persons with FASD remained in the education system until high school but many did not complete high school or receive their diploma. Equally concerning is the fact that seven participants never made it beyond elementary school and ten participants never made it beyond junior high. The limited availability of educational supports and administrative challenges is discussed in later sections of this report.

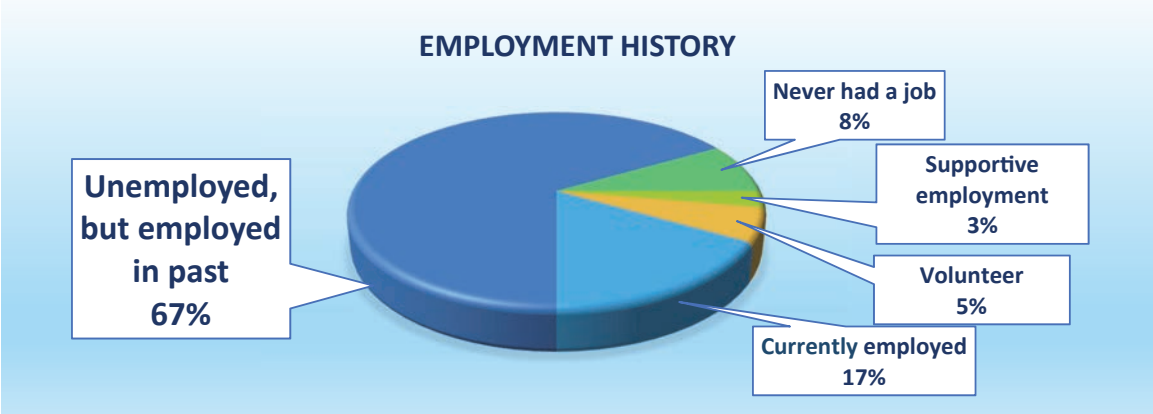
A number of the participants who had adoptive parents tended to have strong advocacy for their needs as persons with FASD. In fact, there were numerous incidents of adoptive parents mentioning a time in which they had written a letter of complaint to a local school principal, a local politician or a local health official This speaks to the level of advocacy skills that appears to be needed to ensure persons with FASD get the services they need. While those participants with adoptive parents or foster parents appeared to have strong advocates for their various special needs, the opposite appeared to be true for those living with biological parents or relatives. In most cases, it appeared not to be a matter of neglect but rather a matter of not having the skills, abilities or capacity to effectively navigate the system and be a strong advocate for the services needed.

## CHART 5.1.6




See chart 5.1.7: When participants were asked about employment, the majority (24) were currently unemployed but had been employed in the past. The fact that over 30 of the participants had a job in the past or were currently employed in some capacity speaks to the willingness of persons with FASD to be employed, if the employment situation is appropriate for their level of functioning. It is worth pointing out that only one participant identified as having participated in a supported employment program.

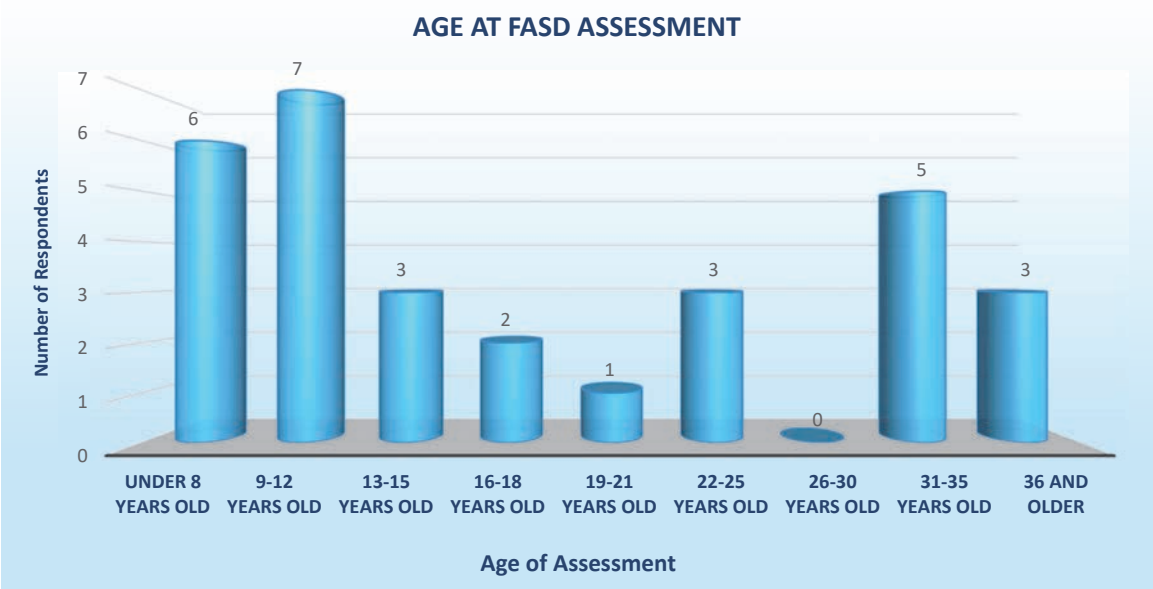
## CHART 5.1.7



# 5.2: FASD Assessment & Diagnosis

See chart 5.2.1: The availability and accessibility of FASD assessments was an issue that was raised time and time again by caregivers, participants and service providers alike. When we look at the graph below we see that the vast majority of the participants were assessed for FASD after the age of 9 (24 participants). There were numerous accounts of caregivers, foster parents, adoptive parents as well as biological parents who had requested an FASD assessment and were told their child would be placed on a waitlist.

### CHART 5.2.1




## How would a diagnosis help you now or when you were growing up?

When persons with FASD were responding to how a diagnosis might have helped them when they were growing up, 45% said it would have made a big difference in their education, citing extreme frustration with things like poor focus and attention span.

*"Yes, absolutely. I had real problems with my attention span in elementary school and it went through to high school. If I had a diagnosis back then I could have got help and not got 51% in every class."*

– Male, 21, Westlock, AB

*"Probably would have helped me when I was younger...and with school. I had trouble focusing in school."*

– Female, 23, Fairview, AB

*"Yes. I probably would have finished school. Struggled a lot in school. I had difficulty focusing."*

– Male, 23, Rocky Mountain House, AB

28% of the persons with FASD maintained getting a diagnosis at a younger age would have meant they would have had a better understanding of the problem and so would their caregivers and teachers; this would have resulted in more understanding and better life choices.

*"Probably. I would have gotten more help in school and made better choices. I ended up marrying a man with FASD when I was 16 years old."*

– Female, 37, Grande Prairie, AB

*"Yes for sure. I wouldn't have gotten into so much trouble. Wouldn't have gone to jail. It would have helped me understand. I would have had a better life."*

– Male, 41, Lethbridge, AB

*"It may have helped to get help and resources. Would have helped avoid being homeless, getting help earlier."*

– Male, 35, Fort MacLeod, AB

## Has receiving a formal diagnosis been helpful for you? Why nor why not?

When persons with FASD were asked if a diagnosis has or has not been helpful, 76% of them indicated that having an assessment had helped them in a positive way, while 9% said sometimes and 15% said the diagnosis was not helpful.

The vast majority of the participant comments fell into one of two categories. In the first category, 52% indicated that the best thing to come out of their assessment and formal diagnosis was the fact they were able to access services and supports.

*"Yes because it hooked me up with programs that support me. It also explained a lot to me; like the way I am."*

– Female, 40, Medicine Hat, AB

*"It explains why I am the way I am. It helped me get on to AISH. It also got me into special needs classes."*

– Male, 23, Rocky Mountain House, AB

*"Yes. It helped get AISH. I had no supports at all…now I get more help with day-to-day stuff and setting goals.*

– Female, 48, Lethbridge, AB

In the second category a further 48% said the assessment helped them to "understand themselves". In addition to highlighting the need for early assessment, these statements illustrate the confusion felt by individuals who don't understand the cause of chaos in their lives.

*"Yes. I have been able to understand myself better. I know I can't hold a full time job and I don't get so frustrated."*

– Male, 19, Fort McMurray, AB

*"Yes because it helped me understand why I am struggling in so many ways…and learning abilities, why I get overwhelmed, why I lack patience."*

– Female, 59, Calgary, AB

*"Yes because I notice a difference. I understand learning needs, I used to have "fits" and didn't know why. I understand my anxiety. I really didn't know why until I was 15 years old. They helped, they explained why I didn't act my age. I was able to understand my brain and behaviour."*

– Female, 25, High River, AB

## Who explained FASD to you and how?

When asked who explained FASD to them, 32% of the persons with FASD indicated that it was their identified support worker. A further 32% of the participants indicated that it was their parent or foster parent who had explained FASD to them. The remainder of the participants indicated they did their own research on FASD or their doctor explained it to them. It might be worth noting of the 37 FASD participants we interviewed only one mentioned a teacher being part of their FASD explanation. Furthermore, only one participant mentioned a mental health clinician being part of the explanation. Not one participant mentioned addiction staff as being helpful or supportive in this regard.

If FASD education is more effectively delivered through an objective third party, such as a support worker, then the importance of that team member can't be understated. As many of the participants stated, understanding their diagnosis was key to understanding themselves and understanding themselves was key to making more informed choices and minimizing the dysfunction in their lives.

To illustrate this importance further, consider the common theme that the FASD explanation is an ongoing need and not simply a one-off explanation. Some participants indirectly indicated it was an ongoing need that required ongoing education and in some cases almost daily reminders. This really validates the vital role of the FASD support workers and the FASD support services that employ them.

*"I figured most of it out on my own but J. from [Family service Provider] helps me out a lot."*

– Male, 41, Lethbridge, AB

*"[FASD service provider] has made a big difference in my life. Helping me to understand myself."*

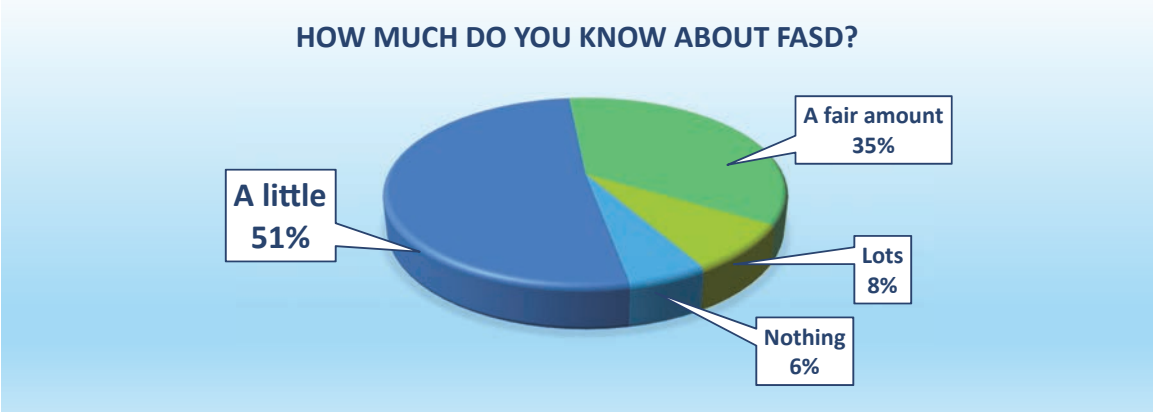
– Female, 37, Fort McMurray, AB

*"My mentor and I talk about it a lot."*

– Male, 42, Hinton, AB

See chart 5.2.2: When participants were asked how much they knew about FASD, 51% said they knew a little while 43% said they knew a fair amount or more. If one considers 51% said they knew a little, and 6% said they knew nothing, you arrive at 57% who knew a little about FASD or less.

### CHART 5.2.2



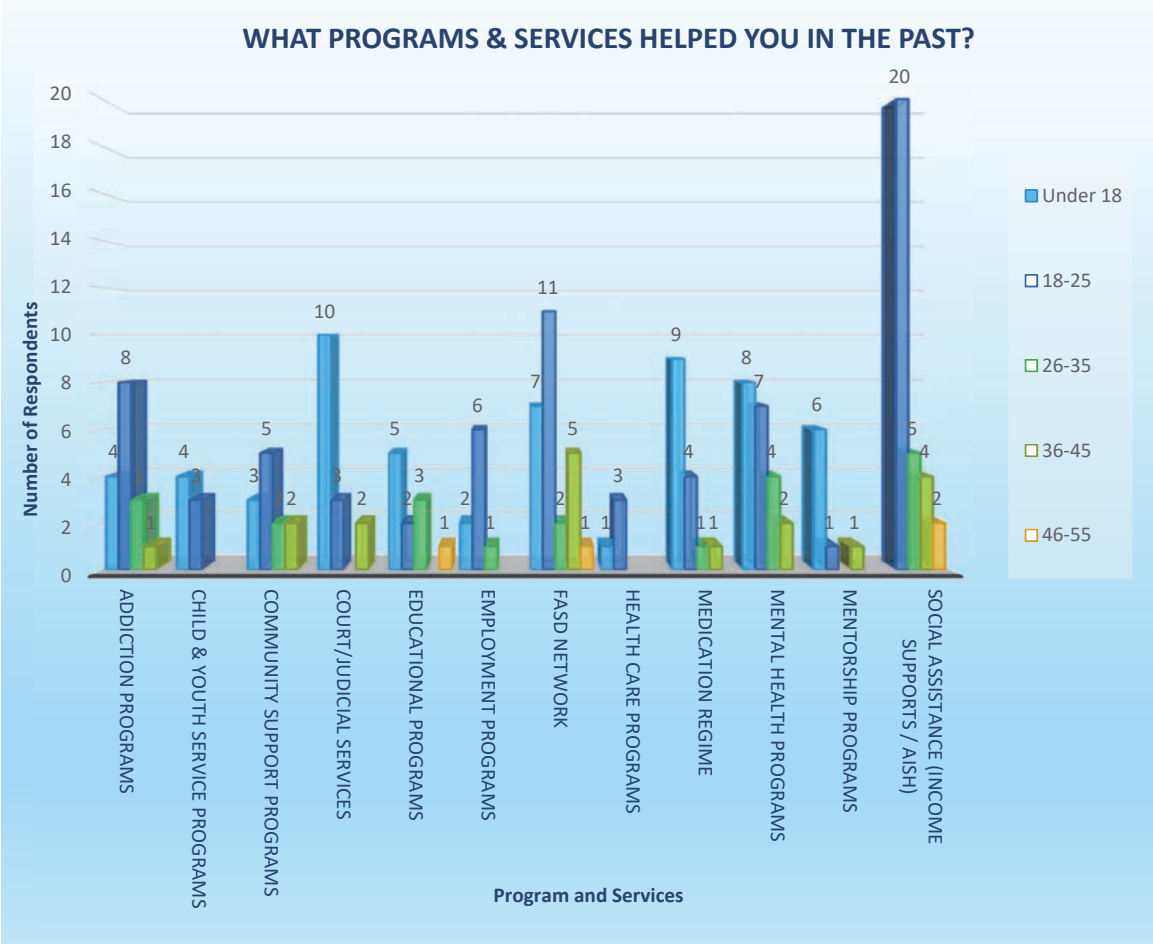

If persons with FASD are telling us that understanding their diagnosis is essential to well-being and they're also telling us that it is an ongoing educational need, perhaps there is a greater role for other professionals to play in the FASD explanation and ongoing education. Teachers would be well-positioned to support this educational need given their area of expertise and time spent with the student. In those cases where substance abuse is present, addiction counselors would also be well-positioned to provide this support. Finally, in cases where mental health is an identified concern, mental health clinicians would also be well-positioned to provide this support.

# 5.3: Community-Based Services & Supports

The persons with FASD were very vocal about the importance of various support services and support staff. Many of these participants have daily reliance on their identified support worker to ensure they get to their appointments on time and remember other important adulthood responsibilities like paying a phone bill or buying groceries.

See chart 5.3.1: While participants were under 18 years of age, it would appear that court/judicial support services, the FASD Network, mental health services and a medication regime made up the bulk of their support service and care plan. While participants were aged 18-25 the focus of support service involvement shifted to AISH, Social Assistance, the FASD Network and Addiction and Mental Health programs. From age 26 on, it would appear that the involvement of multiple support services in general tends to decrease.

## CHART 5.3.1



## Which program/service was the most helpful to you?

The overwhelming majority of the persons with FASD indicated that their identified support worker was the most helpful service to them (60%). In some cases that support worker was employed by the FASD Network; in other cases the support worker was employed by a contracted service provider. Regardless of who employed the support worker, it was clear they were the biggest source of support and absolutely vital to day-to-day functioning.

*"D. at [Family service provider] is my support worker. She helps me remember my appointments, helps with transportation, supports with addiction, and supports with court matters."*

– Male, 39, Athabasca, AB

*"Probably J. at [Family service provider] she helps me with a lot of things I don't understand or when I get confused with things."*

– Male, 41, Lethbridge, AB

*"[Family service provider]and the [FASD service provider] have been really helpful. They support me with difficult things like applications and services (i.e., AISH)"*

– Male, 23, Rocky Mountain House, AB

*"[Family service provider] and [Family service provider] gives a lot of knowledge, insight on how to do things. Help put things together for parenting, children and resources. They get speakers in to talk. Lot of tools. Provide respite care. (They build) trust and you're able to be open."*

– Non-binary participant, 48, Lethbridge, AB

## What was least helpful program/ service to you and why?

When asked what the least helpful program was, the answer was clear. 30% of the participants indicated that Addiction and Mental Health staff were the least supportive. A further 12% of participants stated teachers and schools were less than helpful, 12% indicated it was other community based staff and or FASD Networks staff that were not helpful.

*"The inpatient mental health staff were not very helpful as they didn't understand FASD and how it affected me. They had sent my prescription to the wrong place when I was discharged."*

– Female, 37, Grande Prairie, AB

*"Mental Health wasn't very helpful. School wasn't very helpful."*

– Female, 25, High Level, AB

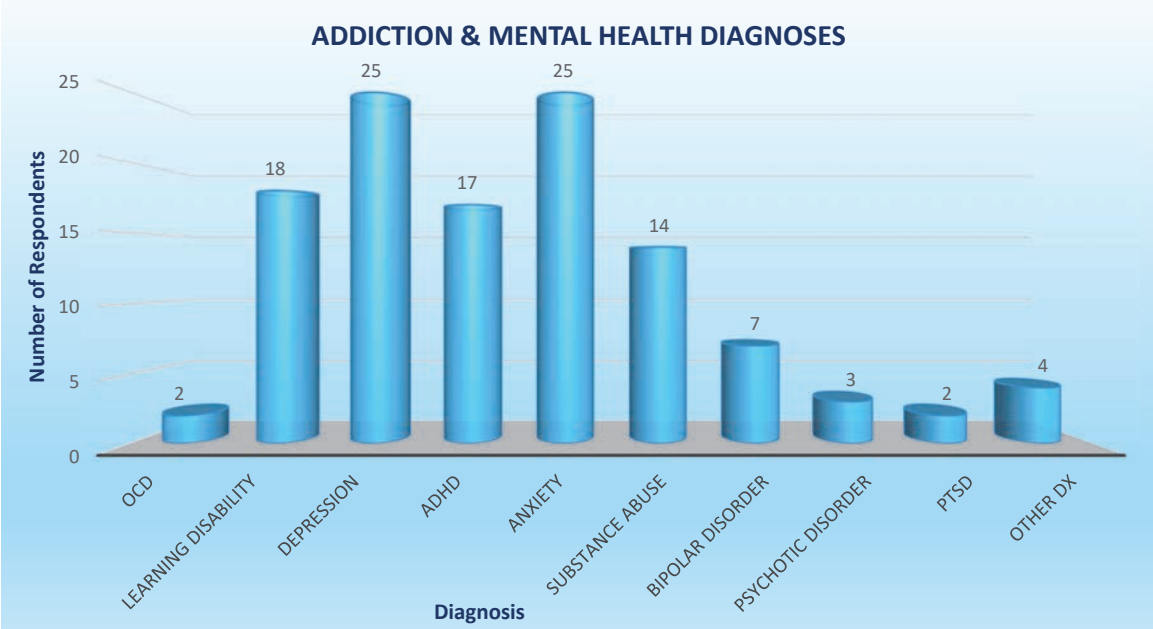
*"Addictions has not been helpful because I wanted to go to treatment and they wouldn't help me get into a place. I felt really discouraged every time I've seen her. I ended up getting into treatment on my own."*

– Female, 37, Fort McMurray, AB

# 5.4 Addiction & Mental Health Services

See chart 5.4.1: All the persons with FASD in this project indicated they had one or more addiction or mental health diagnoses in the past. Depression and anxiety were the two diagnoses most commonly cited with 25 people stating they've had these diagnoses. ADHD and learning disabilities were nearly as commonly cited with 17 and 18 participants claiming the diagnosis respectively. Substance abuse was also quite commonly cited with 14 participants stating they've had issues with substance abuse.

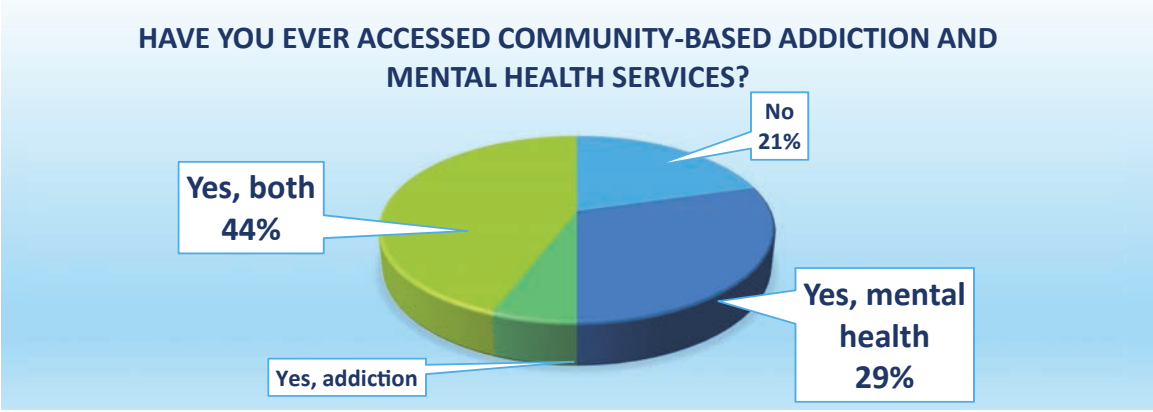
## CHART 5.4.1




## Have you ever accessed community Addiction and Mental Health services?

See chart 5.4.2: At 79%, the overwhelming majority of the participants had accessed community-based Addiction and Mental Health services in the past.

## CHART 5.4.2



## Which Addiction & Mental Health services were the most helpful to you?

When asked which Addiction and Mental Health services were the most helpful, 41% of the persons with FASD indicated mental health was most helpful (namely the counsellors, the mental health workers and the Community Outreach and Assessment Support Team). In cases where the participant cited mental health services as being the most helpful, it was most often a psychiatrist and usually related to a prescription. Conversely, in those cases where the participants cited addiction services as being the most helpful, it was most often because that particular addiction service was able to get them into an addictions treatment facility.

*"Mental health eventually got my prescription correct. They were able to give me a monthly injection and bubble packs."*

– Female, 37, Grande Prairie, AB

*"Mental Health, my depo shot"*

– Male, 29, Medicine Hat, AB

*"Addiction services were helpful. They helped me get into treatment like 3 times."*

– Male, 48, Westlock, AB

*"Addictions counselor. Treatment 5 times"*

– Male, 26, Rocky Mountain House, AB

## What was the least helpful thing about these services?

In terms of which was the least helpful service, 43% of the persons with FASD felt that mental health was the least helpful due to things such as ineligibility to access mental health, long waitlists, lengthy times between appointments, the strategies used in counselling didn't seem to work, inexperienced psychiatrists, inadequate support staff and a sense of indifference (i.e. not wanting to help).

*"Mental Health was a waste of time because it felt like they didn't want to help me. They just sent me to addictions."*

– Female, 48, Lethbridge, AB

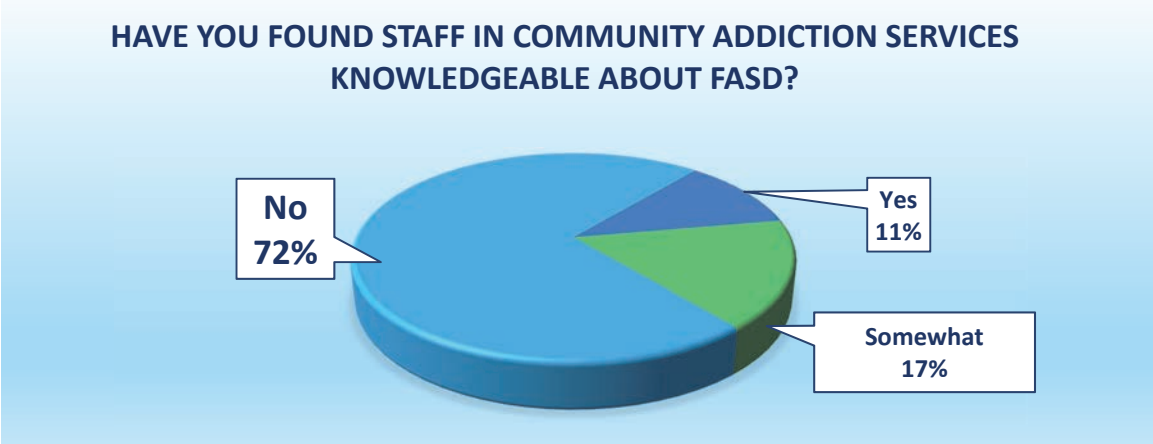
*"I was initially told I couldn't access mental health because I was an addict. So I stopped using and went to mental health and they told me I was fine."*

– Female, 40, Medicine Hat, AB

## Have you found staff in community addiction services knowledgeable about FASD?

See chart 5.4.3: When participants were asked if community addiction staff were knowledgeable about FASD, a strong majority (72%) of them stated they did not think addiction staff were knowledgeable about FASD. In fact, only 11% of the participants believed addiction staff were knowledgeable about FASD.

### CHART 5.4.3




## Have you found staff in community mental health services knowledgeable about FASD?

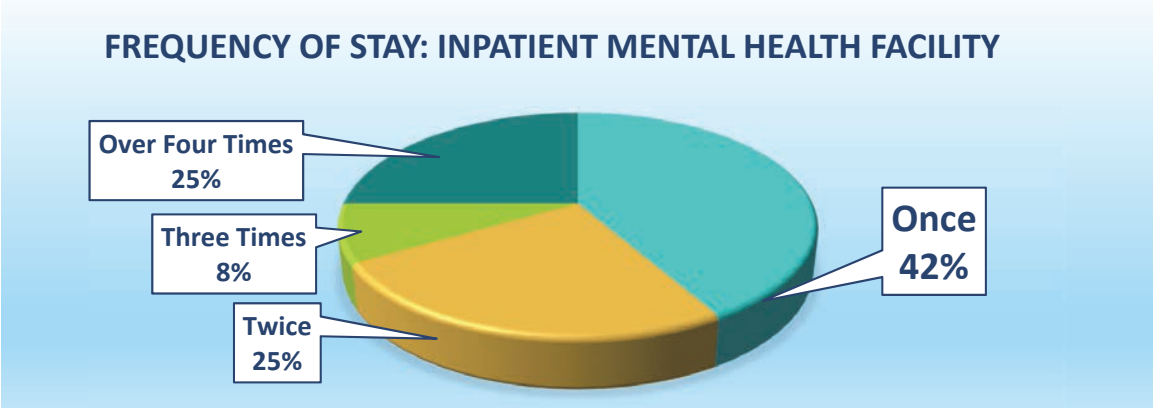
See chart 5.4.4: When participants were asked if they felt community addiction staff were knowledgeable about FASD, the results were a little better with 39% of the participants saying “yes” and 33% saying “somewhat.”

### CHART 5.4.4

## Have you ever stayed in an inpatient mental health facility?

See chart 5.4.5: When participants were asked if they had ever stayed in an inpatient mental health facility, 40% said 'yes' and 38% said 'no' (with 22% being not applicable). Of those who acknowledged inpatient mental health stays, the frequencies of stays were as follows:

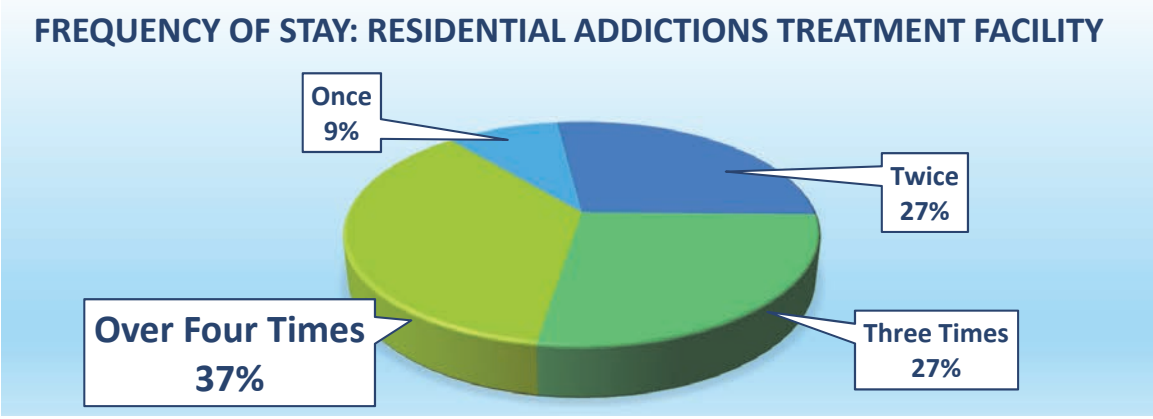
### CHART 5.4.5




## Have you ever stayed in a residential addiction treatment centre?

See chart 5.4.6: When participants were asked if they had ever been in a residential treatment facility for addiction, 41% said 'yes' and 35% said 'no' (with 24% being not applicable). Of those who acknowledged residential treatment facility stays, the frequencies of stays were as follows:

### CHART 5.4.6



## If yes, what about the services did you find helpful to you?

A total of 43% of the persons with FASD had stayed at an inpatient mental health facility, a residential addiction treatment facility or both at one time or another. When asked what they found helpful in inpatient treatment, 46% indicated that learning was most helpful, 31% indicated the interaction was most helpful and 15% reported that specific programming was helpful, such as a women's only group or a spiritual cultural component (such as smudging, sweatlodges or healing circles).

*"It was helpful for a little while but I always relapse. I like the food, I liked the interaction with other clients. I especially like the Indigenous programming and trauma recovery. Talked about intergenerational trauma."*

– Male, 32, Lethbridge, AB

*"I like listening to the stories of other people. I recognized a lot of the same stories and the same patterns."*

– Male, 41, Lethbridge, AB

*"Yes, everything was very helpful. It was hard at first but I learned knowledge each time and I put it together and it helps me every day."*

– Male, 35, Fort MacLeod, AB

*"[Addiction service provider]…spiritual side…smudging, prayers, sweats, healing circles, etc. It's a wonderful healing place. I connected with a counsellor and she helped a lot, I started talking about my life. I also had a very helpful Indigenous counselor."*

– Female, 59, Calgary, AB

## If yes, what about the services did you find least helpful to you?

Of those participants who went to an inpatient mental health facility, a residential addiction treatment facility or both, 20% felt the facility had rigid rules, schedules and structures that were unnecessary.

*"It seemed like the rules of the treatment centre were unnecessary and drove a wedge between my friend and I."*

– Female, 29, Medicine Hat

*"I didn't like the early morning wake up calls and the structure…all the chores."*

– Male, 32, Lethbridge, AB

*"Wasn't helpful at all. The places was so boring. We weren't allowed anything. They didn't know how to handle their own patients. They didn't even try to get to know their patients…they need to know the patient if they wants to help them. All they do is give people medication."*

– Male, 25, Edmonton, AB

Another 20% of the participants felt the programming was not helpful because of its lack of spiritual component, the structure of programming (i.e., classwork or group size or type of group) and or its suitability for individuals with FASD.

*"I didn't really like some of the programming…sometimes it was like a classroom with homework and I don't like learning that way. I like learning with people together."*

– Male, 48, Westlock, AB

*"Wanted help but it was hard to understand. Long time ago, was kind of a joke. Wasn't helpful. Went to some kind of anger program too and don't remember being receptive to it."*

– Non-binary participant, 48, Lethbridge, AB

*"[Addiction service provider]…don't have spiritual program, no ability to practice"*

– Female, 59, Calgary, AB

Finally, 20% felt that there was a lack of rapport, trust building and listening skills from the staff as well as a lack of experience in addiction staff.

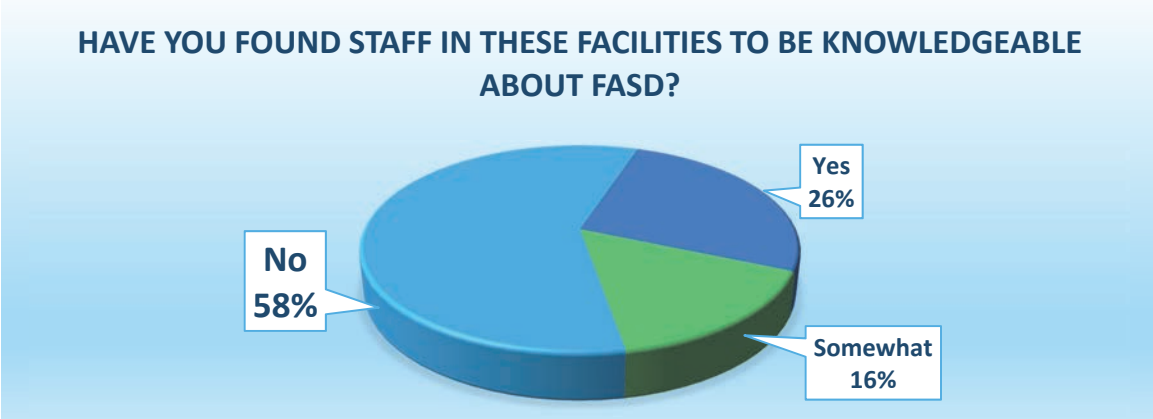
*"Some of the counselling. Counsellors had no experience with addiction, so it deterred people from opening up. Also length of time could be longer to be in the program. Also need people need follow up after you are done for relapse prevention."*

– Male, 35, Fort MacLeod, AB

## If yes, have you found staff in these facilities to be knowledgeable about FASD?

See chart 5.4.7: When participants were asked if they felt the inpatient staff were knowledgeable about FASD, 58% said no while 26% said yes.

### CHART 5.4.7



# 5.5 Health Services & Supports

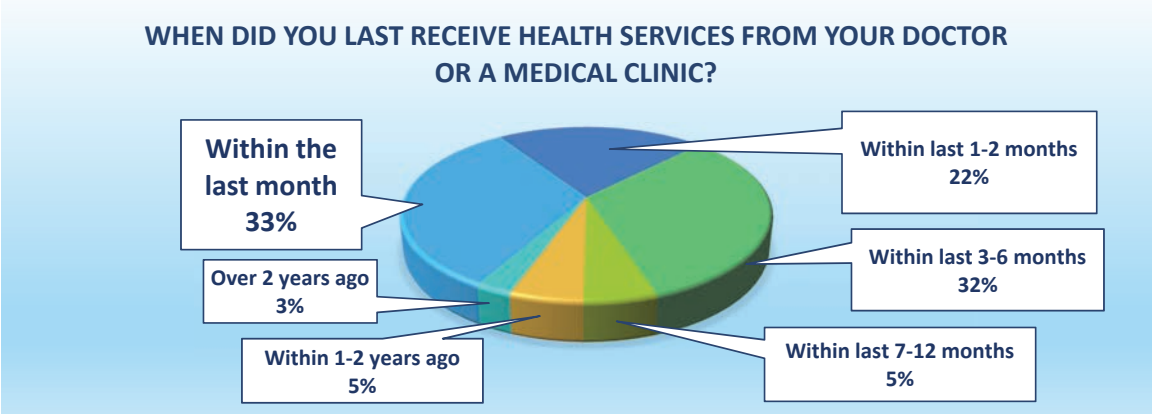
## Do you have a family doctor?

When participants were asked if they had a family doctor, 89% said they did, while 11% said they did not, choosing instead to access primary health services through walk-in clinics or other health service facilities.

## When did you last receive health services from your doctor or medical clinic?

See chart 5.5.1: When participants were asked about the last time they received health services from their family doctor or clinic, 33% said they had seen their preferred source of primary care in the last month, with a further 36% saying they had seen their doctor in the last 3 to 6 months.

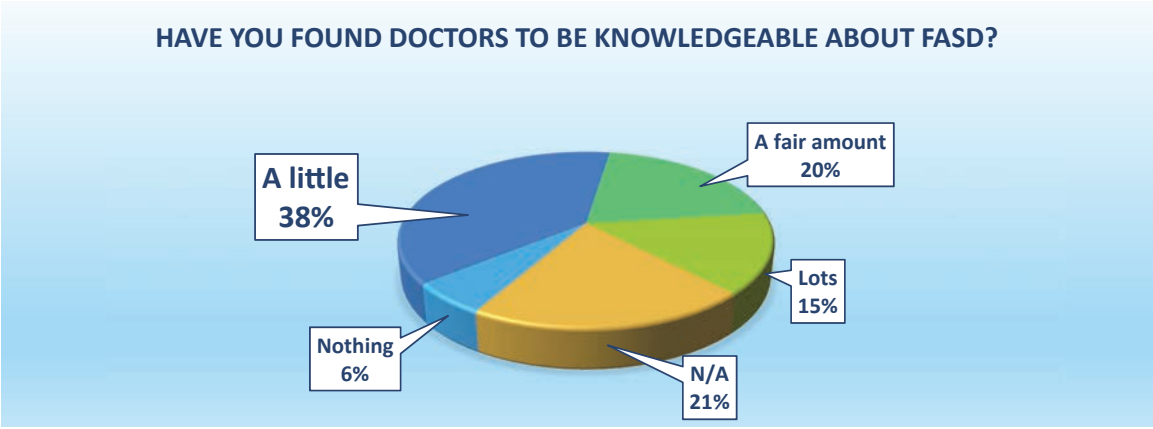
### CHART 5.5.1




## Have you found family to be knowledgeable about FASD?

See chart 5.5.2: When participants were asked if they felt their family doctor was knowledgeable about FASD, over half indicated their doctor knew between a little and a fair amount.

### CHART 5.5.2



## Do you take medication (for conditions related to FASD)?

When we asked participants if they took medication for conditions related to FASD, 35% said 'no' while 65% said 'yes' (it should be noted that 'conditions related to FASD' referred to cognitive and mental health issues only).

## If you do take medication, does it help you?

Of the 23 persons with FASD that answered this question, 65% indicated they were currently taking medication and experiencing various side effects while over 30% said the medication did not help.

Of those taking medication, 41% indicated they struggled with tiredness, sleepiness or drowsiness. A further 12% indicated they struggled with headaches and another 12% said it made them nauseous. The remaining side effects consisted of low energy, increased anxiety, loss of appetite, weight gain and, itchiness.

*"I was on medication but I quit 7 weeks ago. I didn't feel quite like myself. I felt hollow."*

– Male, 25, Edmonton, AB

*"Get really tired, I zone out, fall asleep"*

– Female, High River, AB

*"Makes me very low energy… can't do anything"*

– Female, 48, Lethbridge, AB

*"I get tiredness, low appetite, nausea, headaches, anxiety"*

– Female, 22, Grande Prairie, AB

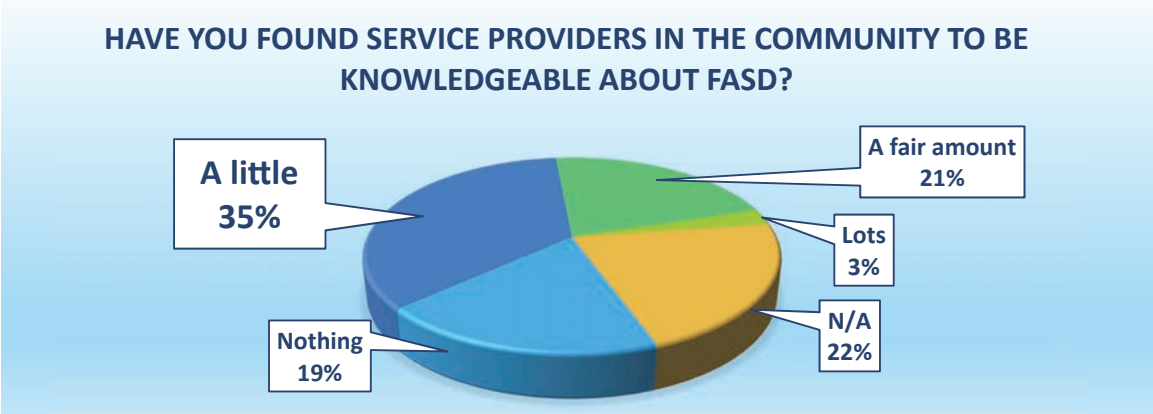
One of the commonly identified challenges of medication was the ability to remember taking it. In fact, a number of persons interviewed indicated they had gone to a depot injection because of their inability to remember to take their medications.

## 5.6 Community Awareness

Have you found service providers in the community (not Addiction and Mental Health) to be knowledgeable about FASD?

See chart 5.6.1: When participants were asked if they felt other service providers in the community (who were not associated with Addiction and Mental Health) were knowledgeable about FASD, 56% indicated they felt like the community knew between a little and a fair amount, while 19% felt community service providers knew nothing about FASD.

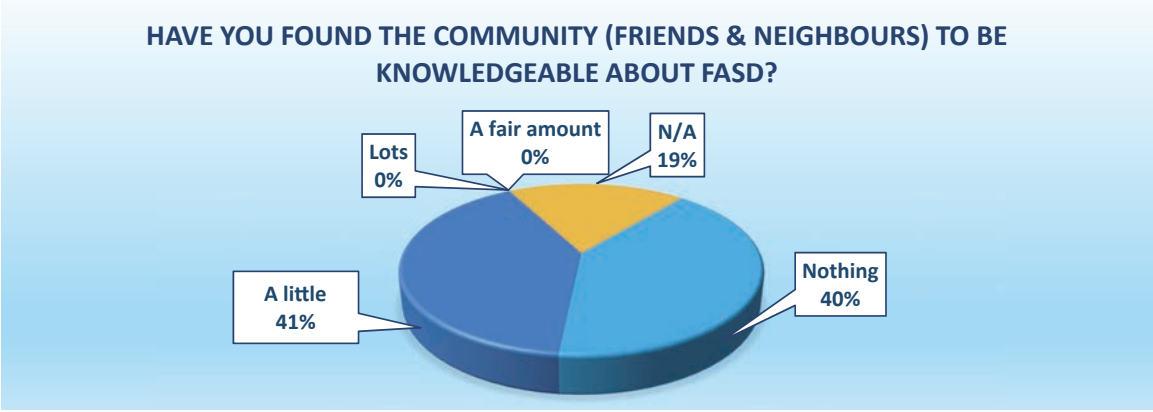
### CHART 5.6.1




### Have you found the community (friends and neighbours) to be knowledgeable about FASD?

See chart 5.6.2: When participants were asked if they felt other members of the community (who were not associated with Addiction and Mental Health) were knowledgeable about FASD, 41% indicated they felt like the community knew a little about FASD while 40% felt community members knew nothing about FASD.

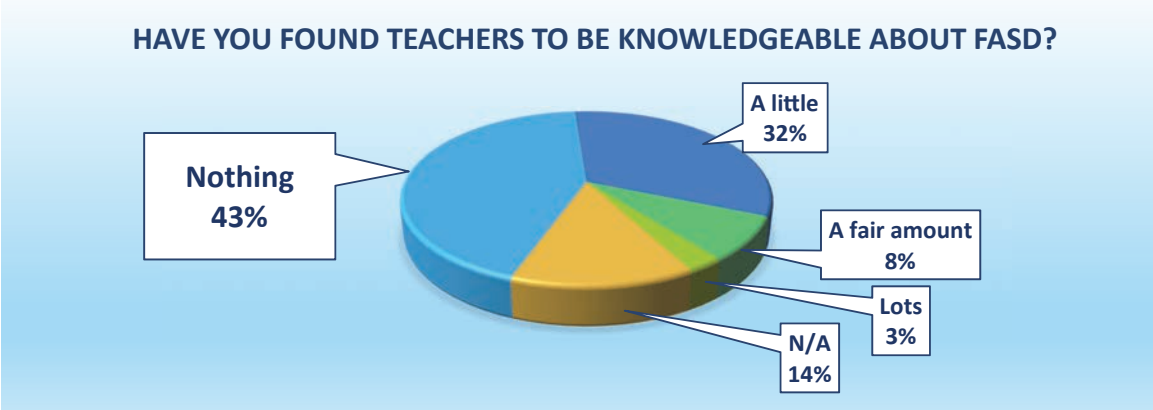
### CHART 5.6.2



## Have you found teachers to be knowledgeable about FASD?

See chart 5.6.3: When participants were asked if they felt teachers were knowledgeable about FASD, the majority of the participants stated teachers knew nothing about FASD (43%). Still some participants felt teachers new a little (32%) about FASD. Only 3% of the participants felt teachers knew a lot about FASD.

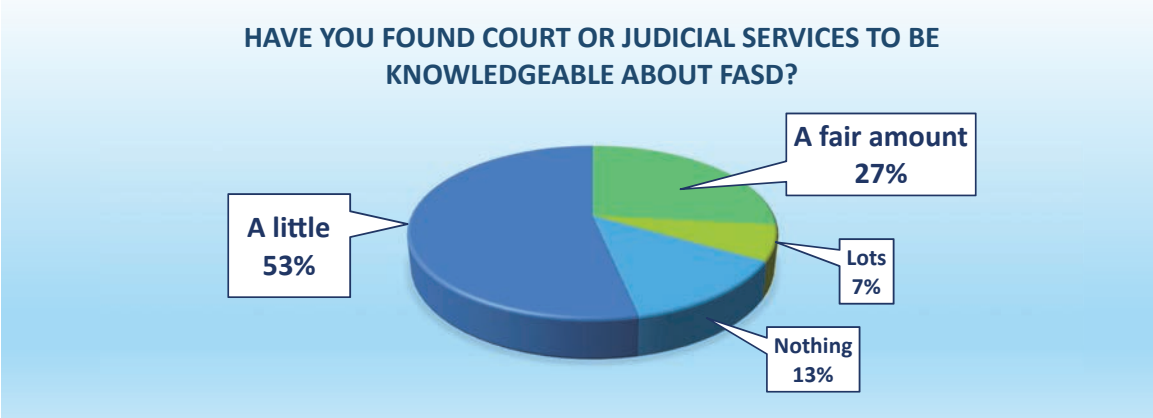
### CHART 5.6.3




## Have you found court or judicial services to be knowledgeable about FASD?

See chart 5.6.4: 40% of the adults with FASD had ever had involvement with the police and justice system. When those participants were asked if they felt court or judicial staff (judges, prosecutors, lawyers, probation officers etc.) were knowledgeable about FASD, 53% said they thought judicial services “knew a little” while 27% felt they knew “a fair amount.”

### CHART 5.6.4



### Who in your life is most knowledgeable about your FASD?

When we asked the participants who was the most knowledgeable about FASD in their lives, 54% said it was their FASD support worker, 41% said it was family or extended family members, with half of these being the mother of the household.

*"Probably my support worker at the Network."*

– Male, 21, Westlock, AB

*"K. (FASD Support worker). She has helped with everything. Has helped me get testing, finding out about my background, got me relapse help etc."*

– Male, 35, Fort MacLeod, AB

*"Probably Betty (FASD Support worker) or B. my FASD Support worker or S. my ex-mother in-law."*

– Female, 37, Grande Prairie, AB

*"My mom. She has done lots of research. She has been to lot of groups, conferences, workshops. She understands my feelings and helps others to understand my needs."*

– Female, High River, AB

## 5.7 Care Planning

A robust care plan is essential to supporting the individual and ensuring their needs are met. Persons with FASD often have complex needs requiring the input of multiple services so an individualized care plan is essential. An individualized care plan will not only use the FASD assessment to identify specific needs but will also identify appropriate services to meet those needs.

It is imperative the person with FASD is included in the development of the care plan. Creating a vested interest in the care plan increases the likelihood of the plan's success. It is equally important to ensure the caregiver is included in the care planning process. Ensuring the caregiver is part of care planning process means they will not only be familiar with the plan but will know how they can support it.

### How have you been involved in decision-making about your care?

The vast majority of the persons with FASD were firm in their answer that they made all the decisions regarding their lives (65%). Many of the participants mentioned they were always given a choice or an option in the decision-making process, with an option to change their mind later. 32% of the participants eluded to being the primary decision maker but conceded family, family members and support workers were often on hand to support the decision making process.

*"I make some decisions. I'm involved in some things like my medication. Or when my next appointment is."*

– Male, 25, Edmonton, AB

*"Sometimes…but my dad is in charge."*

– Female, 25, High Level, AB

*"Sometimes I am involved, but my guardian makes the decisions. The guardian never tells me how much money I have or don't have."*

– Male, 23, Lethbridge, AB

## How has your family been involved in decision-making about your care?

Most if not all FASD support services are closed after regular business hours and many of them are closed on weekends. So it is imperative that the family is engaged in the care plan when and where appropriate. Having the family in place to intervene and provide support after office hours ensures the person with FASD has a life line to call in times of crisis. Unfortunately, some FASD behaviours can be challenging, putting strain on families. For this reason, many persons with FASD are estranged from their family.

Of the persons with FASD interviewed, 50% spoke to having support with decision making and were able to articulate examples of that participation.

*"My mom helps me make good decisions, like groceries and paying bills."*

– Female, 25, Edmonton, AB

*"My mom controls my AISH income so she is pretty involved."*

– Male, 19, Fort McMurray, AB

Of the participants interviewed, 38% reported that their family is not involved in their decision making about their care due to severed relationships, death of their family member or that they were an adult making their own decisions.

*"(No, not involved)…Not for a long time because of things I have done when I was young."*

– Female, 22, Grande Prairie, AB

*"No not at all. They were not included in decisions due to my substance abuse."*

– Male, 26, Rocky Mountain House, AB

*"No family involvement…they don't return my calls."*

– Male, 42, Lethbridge, AB

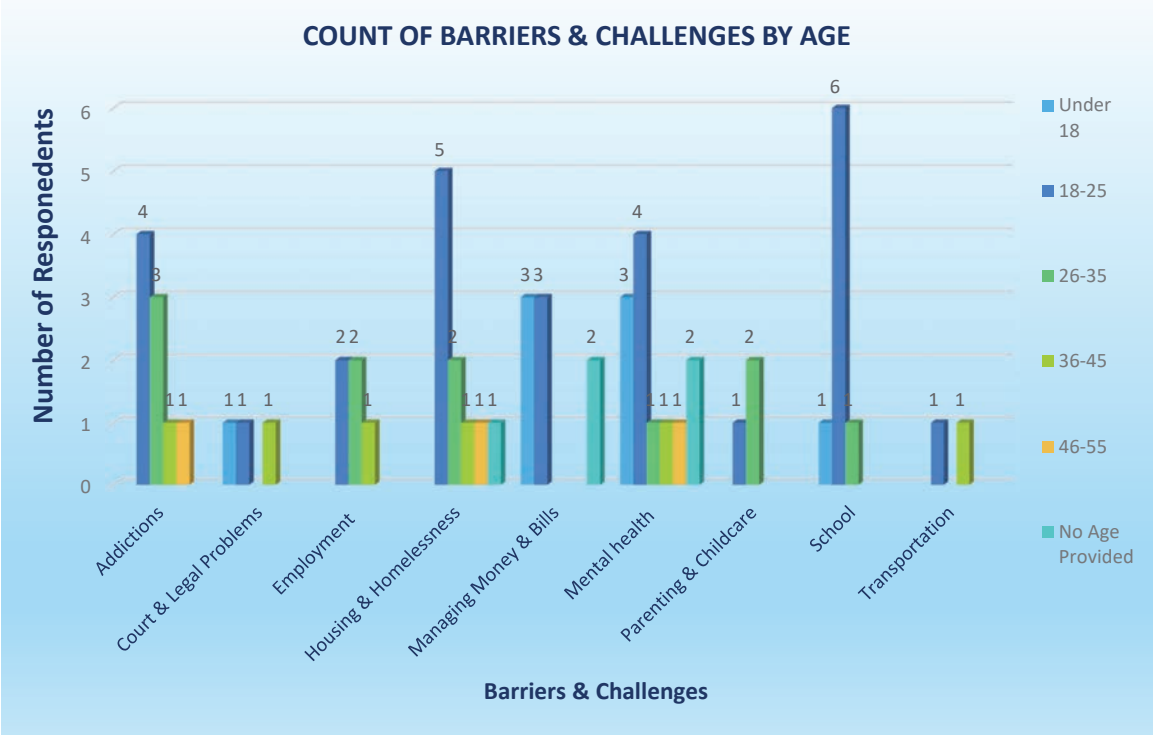
# 5.8 Barriers & Challenges

While ensuring services and supports are delivered in a way that works for persons with FASD is essential, it is equally important to ensure they are accessible. To ensure services are accessible, it is necessary to examine the barriers and challenges to service access and consider how they can be addressed.

## Tell me what the barriers and challenges have been in transitioning to adulthood?

See graph 5.8.1: When the participants were asked about barriers and challenges in transitions, the answers varied but fit into one of the 9 categories listed in the graph below.

### GRAPH 5.8.1



The most commonly cited challenge was mental health (18%), with many of the participants indicating they struggled with impulse control, depression or anxiety.

*"Learning has been very difficult. I get confused and frustrated. Anxiety about socializing is very difficult for me. It leads me to alcohol because I am not so nervous when I've been drinking."*

– Female, 27, Sunchild First Nation, AB

*"Depression. Self-pity. I never give up. Also relying on professionals and services for help. Alcohol and drinking. Not having family. But I've found others who have adopted me and taken me in."*

– Female, 59, Calgary, AB

The next most commonly cited barrier and challenge was housing and homelessness (15%), with many of the participants indicating they had real struggles with housing at different points in their life. Stories of having a house or an apartment and being evicted were common, as were stories of being homeless and living on the streets.

*"Housing is my biggest issue. I have been on the streets for a long time. I think I have been 'red-listed' because I have been on the waiting list for years. Other people get places easy. I never get a call back."*

– Male, 42, Lethbridge, AB

*"I was homeless on the streets of Calgary... living in shelters. I had a number of addictions and get help with a lot of them. I was homeless in Red Deer too."*

– Male, 26, Rocky Mountain House, AB

*"I have had difficulty keeping places because I let people stay with me and they get me kicked out. I have a really hard time communicating with people. When I aged out of care they just told me you're on your own. I lived on the streets of Vancouver for years."*

– Female, 48, Lethbridge, AB

Another commonly cited barrier and challenge was addictions. 14% of the persons with FASD indicated that they had struggles with addiction that affected other areas of their daily life.

*"I have struggled with addictions, housing, homelessness, court and legal problems… addictions cause most of the problems."*

– Female, 25, Lethbridge, AB

*"I struggle with budgeting. I struggle with housing. I did a lot of meth and got kicked out of my place."*

– Male, 42, Lethbridge, AB

Challenges with managing money and paying bills (12%) was also identified as a common theme. Many of the participants indicated they often buy things they don't need or can't afford, while others stated they simply had difficulty remembering to pay the bills.

*"I struggle with paying bills, budgeting and saving; remembering them. I have trouble getting by because AISH is only $1600 a month. Also struggle with Impulsivity."*

– Male, 19, Medicine Hat, AB

*"I struggle with managing my money, buying things I don't need like drugs, and also people take things from me pretending to be my friend."*

– Female, 25, Edmonton, AB

Finally, school was identified as a common struggle (12%). There were a few participants that identified learning difficulties and the resulting frustration as the source of struggle with their education. But many more of the participants indicated they struggled with anxiety and peer socialization saying the eventually dropped out as a result.

*"I really struggled from elementary to junior high. On a social level I was like 2 years behind...struggled to make friends."*

– Male, 21, Westlock, AB

*"Learning has been very difficult. I get confused and frustrated. Anxiety about socializing is very difficult for me. It leads me to alcohol because I am not so nervous when I've been drinking."*

– Female, 37, Fort McMurray, AB

*"I had a hard time socializing in school; from middle school through high school. I am a lot more comfortable speaking my mind now that school over."*

– Male, 20, Fort McMurray, AB

# 5.9 Opportunities for Service Enhancement

## What things are hard for you to manage and what would help you manage home and community better?

When participants were asked about difficulty in managing their day-to-day lives, 25% of the responses pointed to problems with memory. These participants recounted difficulty remembering important things like dates, times, medications, medical appointments and personal hygiene.

*"I struggle with my memory; trying to remember appointments. I struggle with trying to focus…Math and social were very hard for me. I tend to learn better by myself and not around people."*

– Female, 23, Fairview, AB

*"I have difficulty remembering appointments, dates and times. My mind goes blank sometimes."*

– Male, 41, Lethbridge, AB

*"I struggle with remembering doctors' appointments. I need a lot of reminders. I struggle with money management too."*

– Male, 20, Fort McMurray, AB

Participants frequently expressed difficulty managing money. In fact, 19% of the responses indicated difficulty managing financial affairs like paying bills and buying groceries.

*"Finances. I tend to be very impulsive… I need help with saving. Need to employ more strategies."*

– Male, 24, Calgary, AB

*"I struggle with paying bills, budgeting and saving; remembering them."*

– Male, 19, Medicine Hat, AB

*"Financial stuff has sometimes been challenging, budgeting and how to save, dealing with banks and systems. Having agencies to hold money for people…all my life I've been told not to spend and now I can (18 years old)."*

– Male, 30, Lethbridge, AB

In terms of what could help them manage in the community better, 25% of the participant responses pointed towards some sort of coaching, mentoring and socialization that would support them with the development of coping strategies and more effective daily living skills.

*"Would be nice to have more groups for people who have FASD, even classes on cooking, home care, life skills, how to be independent. Learning to do stuff by yourself. Programs for people with disabilities for example help with learning to drive."*

– Female, High River, AB

*"My house cleaning and getting groceries because [Family service provider] doesn't help me with shopping. I also struggle to make meals and cooking. I need help with all of this."*

– Female, 25, Edmonton, AB

*"Finding friends, a network of support, a sense of belonging, it's stressful to try and talk with people other than services."*

– Male, 30, Lethbridge, AB

Finally, 10% of the participant's responses pointed to a need for help with parenting, respite and childcare.

*"We could really use respite for my kids, one of my kids needs 24hr supervision."*

– Female, 37, Grande Prairie AB

*"I really struggle helping my kids with their homework. I forgot appointments from time to time. Sometimes parenting is challenge. Learning to say "no" is difficult"*

– Female, 27, Sunchild First Nation, AB

*"My daughter has behavioural issues and has schizophrenia, she is struggling with life skills…I'm looking at accessing services through the schizophrenia society. My daughter is defiant… acts like a teenager."*

– Female, 59, Calgary, AB

## What do you want to be doing in 5 years' time? 10 years?

When participants were asked what they wanted to be doing in the foreseeable future, the most common response was "working". 43% of the participant responses indicated they would like to be in a part-time job, have a longer term career or have their own business.

*"I would like to have a career or be well on my way to a career in mechanics or small engines."*

– Male, 26, Rocky Mountain House, AB

*"I want to be finished school and have my cosmetology certificate…cutting, styling hair and doing makeup."*

– Male, 26, Rocky Mountain House, AB

Further to being employed, some of the participants were specific about where they wanted to be working. In fact, 16% of the participants indicated that they wanted to be working with animals. Throughout the course of interviewing, caregivers and service providers routinely said persons with FASD work exceptionally well with animals.

*"I want to start a dog grooming shop. I'm great with dogs. I want to go to art school. I'm also thinking about living on my own."*

– Female, High River, AB

*"I'd like to be working as a dog groomer in my own business. Driving my own car and taking my son to school."*

– Female, 25, High Level, AB

*"Saving my money and going on a trip. Go to school to be a veterinarian."*

– Female, 25, Edmonton, AB

Second to working, the most common response was "going back to school" or "training." In fact, 26% of the responses indicated they want to go back to school to finish their grade 12 diploma, get a GED, enlist in a trade skills training program with hands-on learning or go to university.

*"Hopefully working in heavy equipment. My worker from [FASD service provider] found me a heavy equipment operating course. But I'm not sure if this is what I want to do as a career. I have thought about upgrading and maybe going to college."*

– Male, 20, Fort McMurray, AB

*"I would like to go back school and get my grade 12; then I would like to get a certificate to look after old people."*

– Female, 37, Grande Prairie, AB

23% of the participant responses looked at goals like sobriety, parenting and independent living

*"I would have my own place; I would be off drugs with a part-time job. But I would still come here to hang out (support service provider).*

– Male, 42, Lethbridge, AB

*"I want to be reunited with my family, I want to be sober living."*

– Male, 39, Athabasca, AB

## What services could be put in place to make you feel better and in more control of your life so you can use your strengths to reach those goals?

By far the most common response to this question described a personal support person or mentor. 30% of the participants described a person who would act as a daily life skills coach to help them with memory difficulties, keep them both motivated and focused on goals.

*"I think if the services actually listened to your goals and helped me achieve them. I would definitely need a support person to help me every day, help me remember important things. I would also need educational supports."*

– Male, 23, Lethbridge, AB

*"[Disability service provider] can help me find a job. FASD specific supports (Non-PDD) to help me get up, get ready and go to work on time."*

– Male, 29, Medicine Hat, AB

*"Not sure what my goals are. That's why I need help. To figure that out."*

– Male, 21, Westlock, AB

The second most common response, was educational supports. 20% of the participants indicated they would need supports like tutoring to help them with their educational goals.

*"More educational supports, test taking strategies, reading skills, help prioritizing coping with stress."*

– Male, 27, Red Deer, AB

*"Someone to help me with learning and studying. More support; people who motivate me. Support with childcare."*

– Female, 37, Fort McMurray, AB

*"Maybe educational supports; I would need someone to help me with homework and assignments."*

– Male, 19, Medicine Hat, AB

The third most common response was financial support. 14% of the participants indicated they would need more financial support if they were to achieve their goals in the next five to ten years.

*"Definitely need money. Help with babysitters. Maybe someone to help me study."*

– Female, 23, Fairview, AB

*"Financial help would be needed. An application could be made to the grant. Also need some tutoring resources."*

– Male, 23, Rocky Mountain House, AB

Finally, 13% of the participant responses indicated they would need help with childcare if they were going to get to where they wanted to be in five to ten years.

*Childcare would be a number one. I could go to class and do my homework. Help paying for school or finding money for school."*

– Female, 22, Grande Prairie, AB

*"Need help with small business set-up and book keeping. Help with childcare and remembering his appointments and his schooling."*

– Female, 25, High Level, AB

## If you could change anything about the services that you have received, what would that look like?

When asked what they'd change about the services they received in the past, 27% of the participant responses indicated more day-to-day, one-on-one support now and in the past would have helped them the most.

*"It would be better if I had more support with budgeting, cooking, socializing, transportation and education."*

– Female, 18, Edmonton, AB

*"I would like to have had more daily support with things. We don't get a lot of time with own support workers."*

– Male, 19, Medicine Hat, AB

*"Maybe more help with basic life skills, one-on-one help. I only see my worker once a week, I need help daily. It's an everyday struggle."*

– Female, 48, Lethbridge, AB

The second most common response was that they would like to see more public awareness about FASD. In fact, 21% of the participants felt more community and public awareness about FASD would have helped them immensely.

*"I think a lot of the services I received could have been improved with more people understanding FASD and how it affects us."*

– Female, 37, Grande Prairie, AB

*"I would like to see the people in the community; like hospitals and schools; more educated about FASD people in general, not just social workers and counselors."*

– Female, 40, Medicine Hat, AB

*"I think they need more awareness about it. Police officers, teachers and other professionals…also big oil companies. They need to be aware of FASD so they could recognize it's a spectrum and a lot of people are very capable to do these jobs…and they can do the jobs well with small considerations or supports."*

– Female, 29, Edmonton, AB

The third most common response from the persons with FASD was that they would have benefitted from more FASD awareness in schools. 15% of the participant responses indicated they would have benefitted from schools and teachers being more FASD aware, so that teachers were better equipped to support kids with FASD.

*"I would like more to see more services and supports throughout school. That would have been good. The teachers need additional training about FASD. I probably wouldn't have had so much anxiety about going to school."*

– Female, 25, High Level, AB

*"Including FASD knowledge. There's a big need for respite. More services for transitional needs. The education system…the schools need to be more knowledgeable. I have a lot of regrets and shame. The world is cruel."*

– Non-binary participant, 48, Lethbridge, AB

*"Maybe when I was younger…I wish that teachers were more educated about disabilities as well as FASD and other categories. If teachers talked and explained things more…in high school. Kids need someone to help and to talk to and should not get left alone."*

– Female, High River, AB

Another 8% of the participant responses expressed the need for more effective, supportive and responsive Addiction and Mental Health services.

*"There are a lot of aftercare services for women, but not a lot of supports for men after rehab. Only A.A. meetings. What's the point of going to rehab if I am going to end up back at square one?"*

– Male, 39, Athabasca, AB

*"Mental health staff being more supportive and non-judgmental. They always say "reach out if you need help" but when you do they always push you away. Addiction staff who understand FASD and don't judge us. It was always discouraging to see my addiction worker. She always said it's "mind over matter" when she talked about my anxiety. She should have helped me instead of making me feel weak."*

– Female, 37, Fort McMurray, AB

Finally, 6% of the participant responses indicated that having an earlier FASD assessment would have made a big difference in their lives. Most felt that an earlier assessment would have meant earlier access to the many supports and resources that could have helped them early on.

*"I don't know…maybe if I had a diagnosis earlier I would have did better in school… I would have got an FASD worker sooner."*

– Female, 23, Fairview, AB

*"I wish I had supports when I was younger...like in school. I wish I was assessed earlier. I wish I had more daily support. I only see them twice a week."*

– Female, 25, Edmonton, AB

## What are other ideas you might have about what would make it better for individuals living with FASD and what advice can you give to service providers in caring for and working with individuals with FASD?

On this particular question, we invited persons with FASD to speak to anything that we may have missed in the interview. We wanted to give them an unfettered opportunity to voice their concerns and offer their solutions. As one might expect, there was very little in the way of response consensus. However, one could still identify certain themes in the many of the responses provided.

One such theme would be that as a client group they need services and supports to be more open minded and non-judgmental.

*"Keep an open mind; be understanding; understand that we are people with feelings too."*

– Female, 18, Edmonton, AB

*"Services need to be lenient and patient. They need to get to know me and not assume I am a bad person."*

– Male, 29, Medicine Hat, AB

*"Some of us have difficulty understanding people. Sometimes we behave differently…bad. But we are not bad people. We have problems looking for help, asking for help and finding help."*

– Male, 32, Lethbridge, AB

*"Be patient with persons with FASD. Too many times in my life people have given up on me before giving me a chance. I didn't ask for this. I didn't ask to be here. It's not my fault. So just give me a chance."*

– Male, 26, Rocky Mountain House, AB

*"Preconceptions…open minded supports are needed. Everyone with FASD is different, don't assume that people are the same. There might be some overlap but everyone's needs are different... people have misconceptions and misunderstandings, things don't work for everyone."*

– Male, 24, Calgary, AB

Another theme would be that as a client group they require services and supports to be more patient and understanding of their disability.

*"Be more relaxed in order to deal with people with FASD. People need to realize that we do things at different paces, sometimes people need to remember patience."*

– Female, High River, AB

*"More help with people living on the street. More understanding and offering people help and services. Don't give people just one or two chances, give as many as they need."*

– Male, 35, Fort MacLeod, AB

*"Spend time with others like me… interaction. It's one thing to hear it from doctors and professionals but another to hear it from someone like me. I hope people never give up on people like me. It was a huge support network of people helping me or pushing me that made a big difference."*

– Male, 27, Red Deer, AB

Another theme, would be the suggestion that programs find a way to get services and supports to families struggling with FASD earlier.

*"More support for women who struggle with addiction and might be pregnant. More support for kids with FASD at home and at school; to help parents before things get out of control. Especially with parents who have FASD. I can't help my kid with his homework."*

– Female, 37, Fort McMurray, AB

*"People with FASD should be connected to services earlier so they get the help they need sooner."*

– Male, 20, Fort McMurray, AB

*"Education needs to change; needs to help us when we are young."*

– Female, 25, High Level, AB

A final theme that we were able to identify in the responses was that there is greater need for public awareness that aims to breakdown the stigmas associated with FASD.

*"Breakdown the barrier of the stigma of FASD; talk more about it. We don't have to be ashamed about it. We shouldn't have to be ashamed about it."*

– Female, 48, Lethbridge, AB

*"I wish more people knew about FASD. Like people in jails and government and business."*

– Male, 48, Westlock, AB

*"Offer more support with schooling…all levels of education…the community also needs to know more about it…like even seeing a poster when you walk in to a school."*

– Male, 21, Westlock, AB

# Section 6: Implications for Future Planning

The recommendations listed below are suggestions for service enhancement that are based on the perspectives of persons with FASD, their families and the service providers struggling to support them. Some of these recommendations could be implemented immediately with system-level changes in the way we work and deliver client-based services. Others are more complex and may involve revisiting how existing resources are prioritized and deployed. Still other recommendations may require new upfront investment that would promise a longer term social return on investment. One thing is clear, enhancing service delivery in a way that works for persons with FASD and their families will require the commitment and participation of multiple systems of service delivery.

## 6.1: FASD Assessment & Diagnosis

### Increase Access to FASD Assessments and Re-assessments

*"Absolutely…the child will get the services they need early. This means they will get educational supports early too. We have clients who have gone on to post-secondary. Those who are adults and get an assessment have already experienced a lifetime of trauma and in many ways the damage is done. This makes it that much harder to learn new things and adapt. It helps the family understand and they can adapt and change in a way that's more responsive to the disability."*

– Service provider, High Level, AB

Service providers across the province have clearly indicated that waitlists for FASD assessments continue to be a growing problem. Most service providers are allocated funding to provide a finite number of assessments each year. Demand for these assessments is generally greater than the number of assessments available, which means service providers usually operate with a waitlist for individuals needing an assessment. For example, in some parts of the province the waitlist for pediatric FASD assessments is 2 years and the waitlist for adult FASD assessments is 2.5 years. One clinic indicated they were funded for such a small amount of adult assessments per year that had an 8 year waitlist for an adult FASD assessment. The demand for these assessments exceeds the supply and lead to waitlists that grow bigger each year. Further, some service providers expressed concern that the number of referrals for FASD assessments is increasing, which also contributes to waitlist growth.

Increasing quick and easy access to FASD assessments needs to be a priority. The waitlists for FASD assessments in most regions of the province are too long, meaning that children are being assessed later than they should be. The late assessment means that caregivers are often left struggling to understand their child's behaviour. Sanders and Buck (2010) found from their interviews that the most positive experience these parents reported was the relief they felt when they finally received a diagnosis, even though some had to deal with grief and guilt over maternal alcohol consumption and past parenting practices.

A delayed FASD assessment can mean caregivers are struggling without strategies to manage the child's behaviour in the home. Caregivers often have unrealistic expectations of the child that lead to conflict in the home and with siblings. The delayed assessment often means the child is unsupported in a state of confused frustration, not understanding why they have struggles that their siblings and peers do not.

The caregivers, foster parents, adoptive parents and biological parents were clear that the biggest frustration of being on a waitlist for an FASD assessment was watching the child in their care fall further and further behind other children in their cohort because they didn't have the necessary educational supports. Further, the challenge was watching their child grow increasingly anxious or frustrated with school to the point where getting up and going to school had become a major source of conflict. For some caregivers, previous child placements had broken down due the intense school-related conflict in the home.

If services aim to stop the cycle of persons with FASD learning to hate school, quitting school or being kicked out of school, the educational supports will need to be in place for them at a younger age. Without an FASD assessment, educational staff are often ill-equipped to strategize the child's educational plan, so children with FASD frequently fall behind in school and become frustrated in a way that affects their desire to attend. Further, the struggles to learn in the same way as their peers affects their ability to socialize, often leading to isolation or withdrawal. Early FASD assessments are essential to ensuring the caregiver and the teachers have the resources they need to meet the complex educational needs of the child.

Having the FASD assessment early also means there is a greater likelihood the supports they need will be funded, in addition to functional supports needed outside of school. Functional supports such as respite and mentor availability, are crucial to supporting placements and preventing placement breakdown.

It is widely acknowledged that children's' needs for support will change as they grow. According to Dr. Gail Andrew, Medical Director, FASD Clinical Services at Edmonton's Glenrose FASD Clinic (personal communication, October 18, 2018), FASD best practice states that children should be re-assessed 5 years after their first assessment or at the very least when they transition to adulthood. Neither of these are realistic or attainable given the current demand for FASD assessments. Assessment resources need to be positioned in a way that the waitlist can come down to an acceptable level, allowing reassessments to occur at the 5 year mark. This would ensure the child or young adult's needs are reassessed and care plans are updated accordingly. When care plans adequately address current needs, there is less crisis management and therefore less drain and strain put on services like health, education and justice.

# 6.2: Community-Based Services & Supports

## Review FASD Access to Multidisciplinary Teams (MDT) and Ongoing Support

The process of FASD assessment often requires the input of an MDT, with caregivers and their family member having the benefit of multiple clinicians supporting the child's developmental and behavioural needs. However, caregivers throughout the province expressed frustration with the lack of developmental and behavioural supports available to their family member thereafter.

Service providers spoke of having to advocate for their clients' access to these much needed services. Specifically, caregivers and service providers voiced concerns about limited access to multidisciplinary teams (i.e. occupational therapists, physiotherapists, speech and language pathologists and mental health therapists) and how they were either not eligible for these services or the services were not provided locally.

A review of multidisciplinary team access is needed to ensure persons with FASD have access to professional behavioural and rehabilitative services that they need. To address the concerns of caregivers and service providers, access to these services would need to be commensurate with the level of services provided to persons with similar neurological impairments, such as autism.

## Review the Funding and Accessibility of FASD Network Support Workers

*"We need more staffing capacity. We are always struggling with meeting demand… so we need more funding for staffing. We also need to recognize the value in this services and pay accordingly. Some of my staff get paid the same as a McDonald's worker. So why would they work in this field? It should be recognized as a population of health needs like PDD or seniors."*

– Service provider, Lethbridge, AB

Throughout the course of the interviews, persons with FASD, their caregivers and service providers highlighted the importance of FASD support workers, describing them as a lifeline to services and supports. In many cases a caregiver had a family member who was deemed ineligible for services and supports because they didn't meet the services' criteria or they were on a waitlist for an FASD assessment. In these cases, the FASD support worker was instrumental in helping them to get their needs met through other community-based organizations, services and supports.

There were numerous accounts of the FASD support workers who supported a person deemed ineligible for services by helping them fill out applications for identification, for financial support, for housing and for employment. There were accounts of support workers helping persons with FASD to remember their health appointments, their court dates and their bill dates. There also accounts of support workers helping persons who struggled with day-to-day living activities, like washing clothes, buying groceries and paying rent.

Persons with FASD and caregivers were clear that the FASD support workers also played a vital role in advocacy. Caregivers spoke of the FASD support workers advocating for their family member's education, pushing the teachers and schools to provide additional supports when needed. Persons with FASD described their FASD support worker speaking with courts and probation officers to ensure they didn't get in further trouble with the law. Persons with FASD described their FASD support worker advocating for their continued health services, when appointments were accidently missed or forgotten. Persons with FASD described their support worker, advocating for income support when they were unable to access it independently.

Throughout the province, we spoke with numerous FASD support workers who struggled to support homeless clients with FASD. It is clear that FASD support workers are an effective safety net for stopping persons with FASD (or suspected of having FASD) from falling through the cracks. It would seem they are also an effective means of re-engaging persons with FASD with needed services and supports, thereby lifting them out of the cracks. Numerous service providers described FASD support workers as the first line of defence in stopping persons with FASD from being homeless. Many service providers spoke to the need for more FASD support workers so it would be prudent to consider a review of their current staffing needs and associated funding.

## Review Funding and Access Criteria to PDD program

*"PDD supports (are needed)…this means more day-to-day supports, how to budget, how to buy groceries, how to do laundry. Ultimately PDD needs to move the IQ level up or change the access criteria all together so FASD clients could access these services. There are 10 brain domains, IQ or academic is only one... FASD typically have deficits in memory, relationships, social and emotional regulation and comprehension."*

– Service provider, Athabasca, AB

Service providers throughout the province described situations in which certain persons with FASD had complex needs that would best be met through PDD supports, yet they were denied access. There were numerous accounts of caregivers that described a family member incapable of independent daily function but they had an IQ score marginally above the PDD access threshold and were therefore denied program access.

Similarly, service providers indicated that persons with FASD tend to score above the PDD threshold in the adaptability portion of the PDD assessment. The problem with this, they say, is that persons with FASD quite often have well-established survival skills or street knowledge that are often mistaken as high adaptability. Further, the very nature of persons with FASD is one in which they are often seeking approval or praise, so they might complete a task in front of an assessor today and be completely incapable of repeating it independently tomorrow.

In the absence of a robust PDD care plan, caregiver placements can break down and repeated attempts at independent living arrangements can often result in evictions and in some cases homelessness. In fact, numerous service providers indicated that when it came to adults with FASD, PDD supports often meant the difference between a client who had a place to call home and a client who was homeless.

When persons with FASD and their families reach these points of crisis, available support services are scrambled to meet the needs on an ad hoc basis and are frequently inadequate in terms of meeting the longer term need. So it is imperative that persons with FASD presenting with complex needs get the PDD support they need from the outset if they are to maintain any level of structure, stability and ultimately quality of life. It would therefore be prudent to review the IQ portion of PDD assessments in favour of more function-based criteria (i.e. daily living skills and adaptability); especially or at least in those cases where all other PDD access criteria is met.

## Review the Funding and Accessibility of FSCD and PDD Supports

*"Service access should depend on level of functioning or presenting need. If you need help. You need it. It should not have to need a crisis point to get help."*

– Caregiver, Red Deer, AB

Throughout the interview process, there were numerous caregiver accounts of persons with FASD that were stabilized and doing well living with caregivers or independently with the support of mentors, then the mentor services would be withdrawn by FSCD or PDD and the person with FASD would go "off the rails." The caregivers would indicate that they would quite often have to scramble all available resources in a crisis response effort that was disruptive and stressful to other members of the family.

Similarly, there were numerous accounts of caregivers and family members with FASD that were managing well with the support of respite services, then the respite services were withdrawn by FSCD or PDD and things would began to deteriorate rapidly. In some cases the caregivers indicated that they had requested a foster child be moved to a different placement as they were unable to cope without the respite care.

Structure, stability and caregiver consistency are extremely important for persons with FASD so it is imperative that caregivers and families receive all the support they need. Not only are family and placement breakdowns extremely disruptive to the person with FASD and their family, but they have lasting consequences. While interviewing adults with FASD, we found that those who maintained positive relationships with caregivers and family, tended to achieve higher levels of education and employment than those who were estranged from their families. They also tended to have higher levels of relationship stability with less separations and divorce. Whereas persons estranged from their caregivers and family tended to have higher levels of homelessness, community-based addiction and mental health service access and higher levels of inpatient addiction treatment (see Appendix A).

Understanding the importance of placement stability and caregiver relationships, it only makes sense that we equip persons with FASD with the support they need outside of the home while providing the caregiver with the support they need inside of the home. With this in mind, it is imperative that we reconsider the funding and long term accessibility of supports like mentors and respite care, to ensure persons with FASD and their caregivers don't have the rug pulled out from beneath them when they are stabilized and doing well. This would ensure that placements do not breakdown as frequently and support services are not having to scramble in a crisis response as often.

## Assess FASD Need for Affordable Housing, Supported Living Resources and Transition Beds

*"About 70% of clients are Indigenous and about 30% are non-Indigenous. A lot of the Indigenous clients don't have natural or family supports that they can access. We need more community supports to address that gap. We need to establish more housing resources and housing supports."*

– Service provider, Grande Prairie, AB

Throughout the interview process it became clear that housing was by far one of the biggest challenges of working with persons with FASD. In some cases the challenges stem from a limited access to affordable housing. In other cases it is an inability to live independently or limited access to supported living placements.

Throughout the interview process there were numerous accounts of persons with FASD or caregivers who indicated that their family member struggled to find affordable housing. Part of the challenge is that AISH benefits are limited, so in smaller communities, there are only a handful of places that might be affordable to them. In some cases the family members with FASD were forced to live in a tenancy they could not afford, so the bulk of their income went to rent. This meant they had to rely on charity services like foodbanks to ensure they had enough food to sustain themselves.

In other cases, independent living is not always possible or appropriate. Throughout the interview process, there were numerous accounts of persons with FASD that were successfully housed independently and later evicted when they continually forgot to pay rent, broke tenancy rules or had disruptive guests who damaged property. In fact, some caregivers and service providers indicated that property owners in smaller communities were refusing to rent to persons with FASD, resulting in homelessness, criminal behaviour and sometimes incarceration.

In these cases, the more appropriate placement is some sort of supported living arrangement where the individual has the benefit of available support staff in some level or capacity. Unfortunately, there is a dire shortage of available supported living placements in communities throughout Alberta, these types of placements are either full with a waitlist or they are non-existent.

There is also a need for housing at critical times of transitions for people with FASD. Throughout the interview process, there were numerous accounts of persons with FASD being in a state of housing crisis after leaving hospital, addiction treatment or correctional facilities; as they had no place to go. Whether a person with FASD has left addiction treatment or been evicted from a tenancy, there is a real need for accessible transition beds in a supported living setting to address these housing crises.

Housing often anchors the care plan for a person with FASD and their family, and is therefore essential to meaningful intervention. To better understand housing needs, community-based need assessments should be completed to determine the appropriate type and level of housing resources needed.

# 6.3: Addiction and Mental Health Services & Supports

## Review of Addiction & Mental Health Service Access for Persons with FASD

*"If someone has brain damage; they don't have the capacity to stop drinking or doing drugs on their own...so at what point will they ever get mental health services? Because mental health services doesn't help people who are using drugs and alcohol."*

– Caregiver, Edmonton, AB

Throughout the interview process it was clear there were a number of persons with FASD, caregivers and service providers who were unhappy with Addiction and Mental Health service access.

With addiction services, persons with FASD and caregivers indicated there was a lot of confusion and inconsistency about access criteria. There were numerous accounts from people who were told addiction services would not be appropriate for them and they were therefore not eligible for addiction services or supports. There were other accounts of persons with FASD who not only accessed addiction services but had gone to addiction treatment on numerous occasions.

While it is understood that FASD is a spectrum and that no two persons with FASD are the same, it would appear that clearer and more consistent FASD access guidelines are needed to help clinicians with the decision to offer supports to persons with FASD or refer them somewhere more appropriate. Further, those guidelines need to be made available to the FASD Networks and community-based organizations that support persons with FASD, so that inappropriate referrals and client frustration can be avoided.

Similar to addiction services, it would appear mental health also needs FASD guidelines to service access. Indeed there were numerous accounts of persons with FASD that were told they were not eligible for mental health supports until they addressed their addiction issues, so they were sent to addiction services who promptly sent them back to mental health services. Inconsistent messaging about service access is confusing and frustrating to a person with FASD and their families. Further, it is disruptive and counter-productive to supporting persons with FASD in the community.

A review of current policy and procedures pertaining to persons with FASD and Addiction and Mental Health service access is recommended. Consideration should be given to the development of an FASD Patient Pathway that could streamline more consistent decision making of Addiction and Mental Health staff regarding appropriate service access. This will ensure Addiction and Mental Health service access is clear and consistent for persons with FASD, their families and the support services that make referrals.

## An FASD Education & Awareness Strategy for Addiction and Mental Health (AMH)

*"Addiction and Mental Health Services could be improved by staff learning more about FASD, specifically clinical interventions that are appropriate and work with FASD."*

– Service provider, Athabasca, AB

Of the 14 caregivers who had accessed community-based addiction services with an FASD family member, none felt the staff were knowledgeable about FASD. Of the 26 caregivers who had accessed community-based mental health services with an FASD family member, 50% felt the staff were not knowledgeable about FASD. Of the 10 caregivers who had a family member with FASD admitted to an inpatient AMH facility, none felt the inpatient staff were knowledgeable about FASD. When the caregivers were asked how AMH services could be improved, 29% of the responses indicated AMH services could be improved with more staff that are FASD-trained.

Sanders and Buck (2010) interviewed eleven parents and found that when parents realized at the beginning of their journey that something was not right with their children and began to seek professional help, there were difficulties that caused a great deal of frustration, including: a) mental health professionals' lack of awareness of FASD; b) the existence of multiple disabilities that came along with a diagnosis of FASD; c) negative experiences with the mental health system, including side effects from psychotropic drugs prescribed by psychiatrists and d) not knowing how to seek information or how to navigate the system.

In order to respond appropriately and effectively to someone with FASD, AMH staff need to understand the unique needs of persons with FASD and their caregivers; and they need to be able to respond accordingly. Throughout the FASD Patient Journey Project we heard persons with FASD, caregivers and service providers express frustration with the way AMH staff communicated with them, their family members or their clients. They were clear that AMH staff needed more FASD awareness if they were to be successful in engaging and supporting their family members and clients.

Persons with FASD and their caregivers talked about how difficult it was to access Addiction and Mental Health services. We heard firsthand accounts of persons with FASD that missed an appointment due to anxiety, and maybe the absence of a support person or they simply got the date and time mixed up. They would attempt to access the service at a later date and be met with an unempathetic staff member telling them they were discharged from the service due to missed appointments. If AMH services are to be effective for persons with FASD, the staff and service need to be understanding of FASD and flexible in its application of policy.

There were many caregivers and service providers who voiced concerns about the expectations of AMH staff. Caregivers and service providers indicated that persons with FASD have difficulty trusting people, stating relationships often take time to build. Caregivers spoke of AMH staff becoming frustrated with their family member because they were not making progress as fast as other clients. If AMH services are to be helpful to persons with FASD, clinicians needs to be patient, and expectations need to be realistic, attainable and appropriate.

Caregivers and persons with FASD frequently complained about AMH staff using "big words" that they found unhelpful or confusing. If AMH services are to be helpful to a person with FASD, language and communication needs to reflect the client's level of comprehension and understanding.

Service providers voiced concerns about AHS mental health clinicians utilizing cognitive behavioural therapy (CBT). The American Psychological Association says CBT "usually involves efforts to change thinking patterns" ("What is Cognitive Behavioural Therapy?", 2019). Further, The American Psychological Association says this usually involves "learning to recognize one's distortions in thinking that are creating problems, and then to reevaluate them in light of reality; gaining a better understanding of the behaviour and motivation of others; using problem-solving skills to cope with difficult situations; learning to develop a greater sense of confidence in one's own abilities" ("What is Cognitive Behavioral Therapy?", 2019). The caregivers and service providers have concerns that this approach is not effective with FASD populations as they often struggle with cognitive processing, cognitive reflection, recognizing choice and consequence and often have difficulty remembering the coping strategies they were taught. To better support persons with FASD, AMH staff need to offer different modalities for variant cognitive functioning.

Persons with FASD described exposure to highly traumatic experiences in both childhood and adulthood and this was often echoed by their caregiver. Many of the persons with FASD that we interviewed had grown up with their biological families and were removed following child protection intervention. Many of them had suffered through other traumatic events involving substance abuse, domestic violence and even the deaths of family members. Beyond treatment models, AMH intervention needs to be trauma informed if it is to be responsive to the needs of persons with FASD and their families.

If AMH staff were more aware of FASD, staff would be better equipped to deliver supports in a way that was client-centred and responsive to the unique needs of persons with FASD. An FASD Education and Awareness Strategy for AMH would need to stress the complexities of FASD, emphasize FASD as a disability, and emphasize the importance of trauma informed care. An FASD Education and Awareness Strategy for AMH, could inform the development of FASD-friendly services while addressing the frustrations of persons with FASD, their caregivers and collateral service providers.

## Expanding FASD-Friendly Addiction Treatment Options

*"When she was in addiction treatment they did not understand people with FASD. All they were really able to do was to keep her clean but she did not understand a lot of the steps. There was also no transition plan for FASD clients (housing)."*

– Caregiver, Edmonton, AB

Accessing Addiction and Mental Health services can be difficult for persons with FASD. Many persons with FASD have difficulty with memory, struggles with anxiety and quite often have a hard time expressing themselves or advocating for their addiction and mental health needs.

Numerous service providers spoke of their frustration in trying to get their client into addiction treatment. Service providers gave numerous examples of incidents in which a person with FASD wanted to go to addiction treatment and by the time a treatment bed was made available, the person had either changed his or her mind or disappeared back into street life, unable to be located.

Throughout the interview process we heard from service providers who indicated that on the some occasions they were successful in getting a person with FASD into treatment but the person was asked to leave the treatment centre for not complying with rules; like non-smoking. Many persons with FASD have difficulty with cognition and understanding the consequences of their impulsive behaviour, so policies that are rigid in application do not work well with this population.

There are few treatment centres in Alberta that understand the complexities of FASD. Those that can work with these complexities have beds reserved for persons with FASD and feature flexible individualized programming to accommodate their unique needs. In some cases, additional one-on-one supports are provided to help the individual understand the program, the process of treatment and the process of transition back into the community. If we want to improve addiction treatment outcomes for persons with FASD, we need to work with addiction treatment service providers to develop more FASD-friendly treatment options.

# 6.4: Community Awareness

## An FASD Awareness Strategy in Alberta's Public Services

*"They need a world that understands them better. They need more people…. who understand FASD as disability. More Compassion."*

– Service provider, Calgary, AB

Throughout the FASD Patient Journey Project, we heard numerous accounts of caregivers and persons with FASD that were frustrated with the lack of FASD awareness in public and community services. The frustration largely stemmed from interactions with the teachers and schools, health services and staff, police and justice or sometimes just the community in general. Through the course of the project interviews, there were numerous examples of how professionals in public and community services did not understand the complexities of FASD or how best to respond to a person with FASD. Further, when caregivers were asked what the most important element of a community service or support was, the most common response was that the service provider was knowledgeable about FASD.

Like AMH, more FASD awareness is needed in public services. Persons with FASD rely on a lot of public services for day-to-day support, whether in health, housing, education, justice, income supports, disability services or employment services. When these services are unfamiliar with FASD and the challenges faced by persons with FASD, poor service user experience is the likely outcome of service access.

A greater commitment to FASD awareness is needed from the ministries responsible for providing public services to persons with FASD. Persons with FASD quite often find themselves in a state of crisis needing support of public services. When public services are not FASD aware, persons with FASD struggle to understand what is expected of them for service access and engagement. When they are frustrated they are more likely to disengage and not pursue service access at all. When this occurs, the person with FASD will often find themselves in deeper states of crisis, like homelessness or incarceration.

These deeper states of crisis often require more intensive staff intervention, additional agency involvement and often more public resource allocation. Thus, it makes sense to provide persons with FASD access to the support they need now to avoid the more costly crises and service interventions later. A public service workforce that is familiar with the disability is needed in order to facilitate more appropriate responses. Developing a workforce that is more FASD-aware would require far reaching commitment to an FASD Awareness Strategy in public services.

Caregivers and service providers alike were fairly consistent in their call for public services that were more FASD-aware, but they were also clear that a consistent and standardized FASD training platform is needed as an integral component. While many of the service providers had completed the FASD 101 training at some point in their initiation to FASD-related employment, many of the service providers indicated the training was not always accessible. If an FASD awareness strategy is to be successful in Alberta's public services, FASD training needs to be accessible and standardized.

## A Provincial FASD Stigma-Reduction Campaign

*"I have a client who says 'I have FASD can you explain that differently to me please.' This took years to get her to this point. So once the stigma and shame is taken away they can actually ask for help without fear of judgement and get the services they need."*

–Service provider, High Level, AB

Over the years, there have been numerous FASD awareness campaigns that tackled different elements of FASD awareness. Some campaigns chose to focus more on prevention, while others chose to focus more on conversations about FASD. Through the course of the interviews, persons with FASD, their caregivers and their service providers identified one particularly disruptive element of FASD that has largely been ignored in previous awareness campaigns: stigma.

Stigma is especially destructive because the shame of it limits the potential of mothers to come forward and admit pre-natal alcohol use, meaning the mother and the child will not have the immediate benefit of much needed services and supports, like FASD education. Salmon (2007) held two group interviews with six Indigenous women and found there continues to be stigma around FASD education and those who access it. In fact, so strong is the stigma of FASD, the service providers interviewed for this project were concerned about a growing trend of mothers that openly admit abusing various substances during pregnancy but vehemently deny alcohol consumption.

Through the course of the interviews we heard stigma was often a barrier to service access in persons with FASD. Some persons with a confirmed FASD diagnoses refused to accept their diagnosis, adamant they were going to "outgrow it." Many persons with FASD indicated they had never accessed certain FASD supports because they didn't want people to know they had FASD. Likewise, we heard from caregivers who were concerned the FASD diagnoses actually made things more difficult for their child. Caregivers indicated their child was "labeled" after their FASD diagnosis and certain staff were reluctant to provide support afterwards.

Targeted community awareness campaigns can be quite effective in tackling the stigma attached to issues that society has deemed too uncomfortable to talk about. Bell Canada's "Let's Talk" campaign has been particularly effective in tackling the stigma associated with mental illness. According to Bell Canada, 86% of Canadians reported they are more aware of mental health issues since the Bell Let's Talk campaign began ("Let's Talk: Results and Impact", 2019).

A provincial campaign that had specific stigma reduction objectives would go a long way to breaking down the shame and embarrassment of FASD and creating healthier self-esteems in those with an FASD diagnosis. A campaign that facilitated empathetic conversations about FASD could result in a more understanding and welcoming community.

## A Corrections FASD Project

*"There is a huge population out there that have FASD…that have been in and out of jail…that have never been assessed and never received services. Or they have been assessed while in children's' services but nobody told them. Our child's four brothers have FASD diagnoses and only a few of them receive supports; the others are in and out of jail and struggle with homelessness."*

– Caregiver, Edmonton, AB

Flannigan, Pei, Rasmussen, Potts, & O'Riordan (2018) state that "compared with the general population, the prevalence of FASD in justice settings is disproportionately high" (p. 3), with even more offenders meeting the criteria for FASD remaining undiagnosed.

In the community of FASD services and supports, it is widely suspected that a large portion of Alberta's correctional population are persons with FASD. Numerous service providers and caregivers spoke of clients and family members who had been in and out of correctional facilities throughout their juvenile years and adult lives. When speaking about their frequently incarcerated clientele that do not have an FASD diagnosis, the service providers spoke of seeing the telltale signs of FASD; the cognitive delays, the difficulty with memory, the difficulty with times and dates, the difficulty with impulsive or disruptive behaviour and the difficulty with self-regulation or control.

Persons with FASD need a lot of services and supports to help them lead a safe and stable life. The services and supports they need are not abundantly available in correctional centres. Furthermore, persons with FASD are vulnerable as they are often easily manipulated and exploited, so correctional centres can be very dangerous places for them.

*"I believe 65%-70% of incarcerated individuals are somewhere on the FASD spectrum. We need a study of what the real numbers are. We need to develop a way of assessing them while they're incarcerated. A screening tool so that we can assess them in jail."*

–Service provider, Lethbridge, AB

A current state analysis is needed to examine how pervasive FASD is in correctional centres. Further, a gap analysis is needed to examine how persons with FASD fell through the cracks and became incarcerated. By understanding the depth of the problem and the conditions that lead to incarceration we can better plan service interventions on the front end. This would ensure people with FASD are getting the help they need and cyclical incarceration is minimized.

## 6.5: FASD Care Planning

### Develop Transition Planning Pathways

*"I had zero assistance with J's transition… The support service before T. was not as helpful as T. There are so many things about transition I didn't know; things like AISH, I would have to figure out on my own."*

– Caregiver, Kehewin, AB

The caregivers were consistent; transition periods are stressful but they are even more stressful for persons with FASD. Whether it was transition from pre-school to kindergarten, junior high to high school or teenage years to adulthood, persons with FASD had elevated needs for support during high stress periods of transition. In fact there were numerous accounts of foster placements that had broken down, children who refused to go to school or were kicked out and even adults who were kicked out of their first independent living placement.

Children who are covered by the FSCD program are often provided with robust transition planning to minimize the disruption of transition points in the child's development. For those children awaiting an FASD assessment or for those deemed ineligible for FSCD, transition planning is less formal and largely dependent on the availability of FASD Network staff.

Service providers and caregivers indicated the transition to adulthood was a particularly stressful transition because it sometimes meant changes to existing services and supports. Many persons with FASD become dependent on structured routines and struggle when the routine is disrupted. For persons awaiting an FASD assessment or for those deemed ineligible for PDD, transition planning is minimal.

In Bennett's (2009) review, transitional services are identified as one of the most beneficial services to persons with FASD (Brown, Moraes, & Mayhew, 2005, as cited in Bennett, 2009). Transition Pathways could be developed to support the person with FASD and their caregiver, as applicable, through these difficult periods of transition. The Transition Pathways could identify services and supports for the pending transition and help the person with FASD and their caregiver access those services when needed. The transition pathway could be completed by the FASD Network support worker and could include professionals from education, employment, health, and children's services as appropriate. The pathway could be used to identify and anticipate higher service needs and prepare for situations in which services or supports are needing to be scaled back or withdrawn.

## Sharing the Lethbridge "Collective Wisdom" Model

*"Because the area is small, we're very close and collaborative. The Collective Wisdom approach…it's a process that is once a month in which we present a case and other funded agencies and community services come in to support and advise. There can be up to 20 people to listen and strategize a plan. It goes beyond funded FASD agencies, there are other agencies as well…and we all put together a case management plan."*

– Service provider, Lethbridge, AB

Throughout the process of interviews we heard from a lot of caregivers who expressed frustration with services not communicating, collaborating or coordinating services and supports effectively. Many caregivers emphasized that persons with FASD are very complex, needing multiple supports from multiple agencies, so it should be standard practice to coordinate services and supports jointly. One caregiver went as far as saying it "was a cop out" because it was a small community and all the community agencies already knew everything there was to know about her family member.

The community of Lethbridge has come up with a rather innovative solution to this problem. The Southwest Alberta FASD Network met with various leaders from community-based services and formed the Collective Wisdom group. This group is comprised of leaders from key support services that support persons with FASD in the community. Collective Wisdom has had releases of information signed by persons with FASD that have complex needs requiring multiple agency involvement and support. The result is a forum where the complex needs of select individuals can be discussed openly and freely. Community services are able to pool their resources to best meet the needs of persons with FASD and are able to respond in real time. In fact, the crown prosecutor attends some meetings and is able to hear the concerns of certain agencies in response to the arrest of a person with FASD.

Sharing what was learned in the Lethbridge Collective Wisdom model would be a huge benefit to smaller communities that find themselves struggling to communicate, collaborate or coordinate services effectively. Further, it would provide a collaborative template for the community services that are struggling to meet demands with limited individual resources.

## 6.6: Closing Remarks

The recommendations listed above are based on the perspectives of FASD service providers, caregivers and persons with FASD. Service providers, caregivers and persons with FASD were clear: for services to be successful in engaging persons with FASD, they need to acknowledge FASD as a cognitive disability and deliver services accordingly. Acknowledging the FASD service user perspectives and acknowledging their unique service needs will ensure that FASD services are developed and delivered in a way that works for them.

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# Appendix A: Interview Observations: Protective Factors of Caregiver and Family Unit

As caregiver skill set increases, probability of services/supports and stability increases

| Caregiver Skill Set | Family Unit | Services & Supports | Interview Observations |
|---|---|---|---|
| • Highly motivated caregivers<br>• Good communication skills<br>• High level advocacy skills<br>• Highly supportive of care plan | • Highly stable<br>• Highly structured with plenty of routine<br>• Highly supportive family unit<br>• Consistent | • Early assessment<br>• Earlier educational supports<br>• Robust care planning<br>• Robust transition planning | • Higher levels of education<br>• Higher levels of employment<br>• Higher levels of relationship stability<br>• Higher levels of adult housing<br>• Lower levels of addiction |
| • Some caregiver motivation<br>• Moderate communication skills<br>• Medium level advocacy skills<br>• Some support with care plan | • Some stability<br>• Some structure and routine<br>• Some support from family unit<br>• Some consistency | • Delayed assessment<br>• Some educational supports<br>• Some care planning<br>• Some transition planning | • Varied levels of education<br>• Varied levels of employment<br>• Varied levels of relationship stability<br>• Varied levels of adult housing<br>• Varied levels of addiction |
| • Little caregiver motivation<br>• Poor communication skills<br>• Low level advocacy skills<br>• Little or no support with care plan or care plan absent | • Unstable<br>• Unstructured with little routine<br>• Inconsistent support from family unit<br>• Unexpected changes in caregiver, family structure, residence etc. | • Late assessment or adult assessment<br>• Little or no educational supports<br>• Little care planning<br>• Little transition planning | • Lower levels of education<br>• Lower levels of employment<br>• Lower levels of relationship stability (more divorce separation etc.)<br>• Higher levels of homelessness<br>• Higher levels of addiction<br>• Higher levels of incarceration |

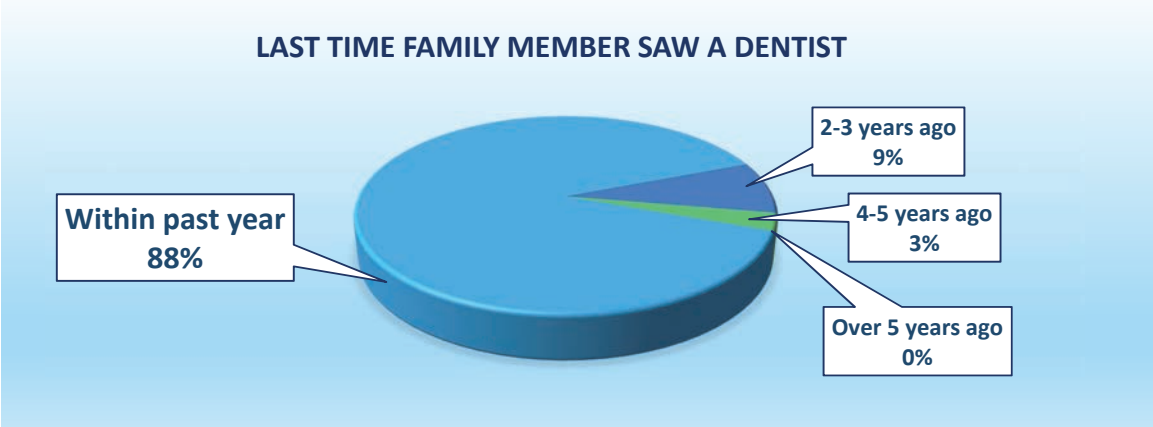
# Appendix B: Caregivers: Dental and Vision Care of Family Members

## Does your child or family member have a dentist?

The majority (83%) of the caregivers interviewed, indicated their family member had a dentist and saw a dentist on a scheduled basis. 17% of the caregivers indicated their family member did not have a consistent relationship with a dental service provider.

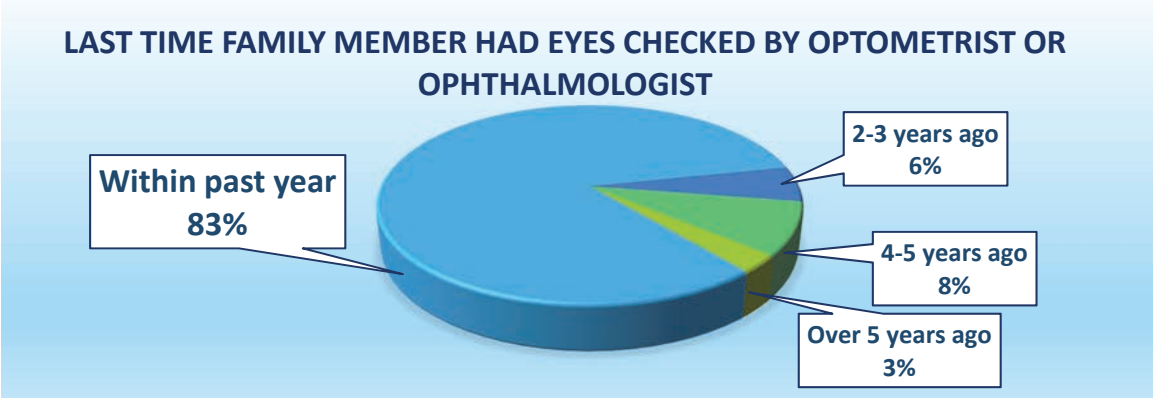
## When did he/she last see his/her dentist?

On the whole it would appear family members with FASD are receiving sound dental care. 88% of the caregivers indicated their family member had visited a dentist in the last year, with the balance indicating they've seen a dentist in the last 5 years.




## Does your child or family member have his/her eyes checked by an optometrist or ophthalmologist?

It would appear the majority of persons with FASD are receiving sound optometry care. Only 8% of the caregivers indicated their family member was not under the consistent care of an optometrist. In fact, 83% of the family members had seen an optometrist in the past year.



# Appendix C: Persons with FASD: Dental and Vision Care

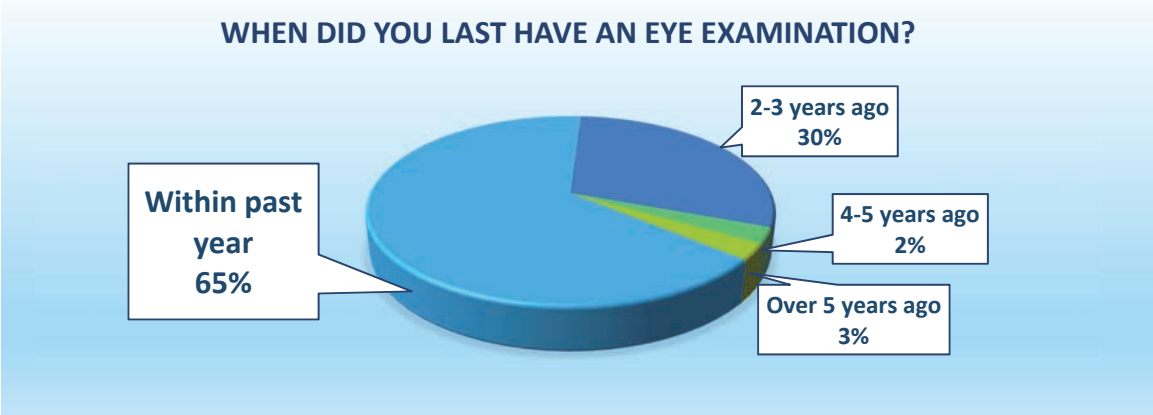
## Do you have a dentist?

When we asked participants if they had a dentist, 65% indicated they did, while 35% indicated they did not.

In terms of dental health it would appear the vast majority of the participants had fairly consistent access to a dentist, with 73% having seen one in the past year.

## Do you ever have your eyes checked by an optometrist or ophthalmologist?

When we asked participants if they had an optometrist or ophthalmologist, 55% said "yes" and 66% said "no."

## When did you last have your eyes checked?

In terms of visual care, the participants enjoyed fairly consistent access with 65% having an eye exam in the last year and a further 30% having an exam in the last 2 to 3 years.