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**ABLE2**  
Formerly Citizen Advocacy

**REVIEW OF THE ONTARIO  
TRILLIUM FOUNDATION (OTF)  
“TRANSITION TO ADULTHOOD”  
PILOT PROJECT FOR YOUNG  
ADULTS WITH FETAL ALCOHOL  
SPECTRUM DISORDER (FASD)**

September 9, 2020



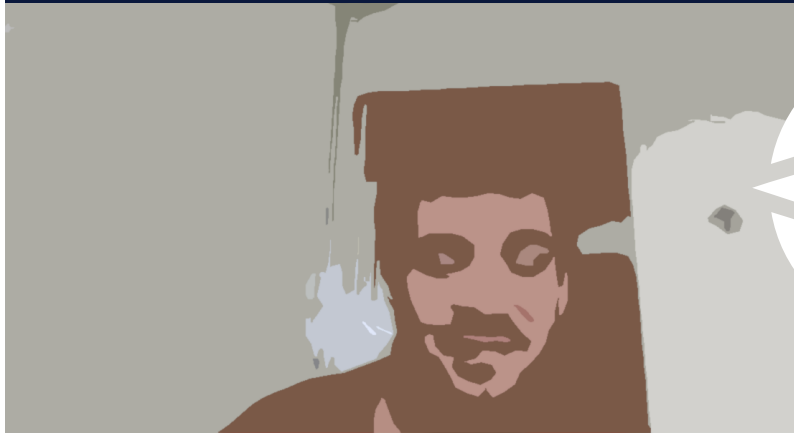
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**15 YOUNG ADULTS  
WITH FETAL  
ALCOHOL SPECTRUM  
DISORDER (FASD)  
TRANSITIONING TO  
ADULTHOOD**



**A TRANSITION  
COORDINATOR MET  
WITH INDIVIDUALS  
FOR 8 MONTHS TO  
SUPPORT THEM TO  
ACHIEVE SELF-  
DETERMINED GOALS**

The goal of the project was to support individuals with FASD transitioning to adulthood to reduce social isolation and feelings of loneliness.



Young adults with FASD needed help with goals such as planning for life after high school, moving out of their parents' place, finding employment, managing their finances, and having meaningful things do to with their time.

# OVERVIEW OF THE ONTARIO TRILLIUM FOUNDATION (OTF) PILOT PROJECT FOR YOUNG ADULTS WITH FETAL ALCOHOL SPECTRUM DISORDER (FASD) TRANSITIONING TO ADULTHOOD



**SUCSESSES**  
Most individuals are less isolated and feeling less lonely after the pilot project.

- ✓ New friendships
- ✓ New connections
- ✓ Boost in confidence and self-esteem
- ✓ Online support
- ✓ Capacity-building



**IMPROVEMENTS**  
The process of planning for goals will likely fail without timely support.

- ✓ Too short and more resources needed
- ✓ Limited by COVID-19
- ✓ Barriers for individuals to get support they need
- ✓ Caregivers would like to be more involved
- ✓ Clarification of the Transition Coordinator role



**COVID-19**  
The pandemic diverted efforts from achieving initial goals.

- ✓ Many goals were stalled or stopped
- ✓ Many placements were interrupted
- ✓ New possibilities emerged for support
- ✓ Increased anxiety
- ✓ Professional challenge



**SUPPORTING INDIVIDUALS WITH FASD**  
Focus on strengths in the accompaniment of the individual transitioning to adulthood.

- ✓ Listen
- ✓ Do not judge
- ✓ Delicately persist
- ✓ Be organized
- ✓ Repeat and be consistent



**TRANSITION TO ADULTHOOD**  
Prevent vicious circles of poverty, homelessness, mental health and addiction issues.

- ✓ Dysmaturity and anxiety
- ✓ Challenges include life after high school, moving out, finances, making friends
- ✓ Lack of support after turning 18
- ✓ Being an adult means having rights and more responsibilities
- ✓ Hand-holding analogy



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## Program Evaluation

### Overview of the Pilot Project

In 2019, ABLE2 (formerly Citizen Advocacy Ottawa) received a Seed Grant from the Ontario Trillium Foundation (OTF). The project aimed to support 15 young adults with Fetal Alcohol Spectrum Disorder (FASD) during the difficult transition to adulthood. Each individual was matched with a Transition Coordinator, assisting them to connect with community resources and to nurture social relationships, thus reducing social isolation and feelings of loneliness. The Transition Coordinator's role was to mentor the individual to help them with individualized goals, such as finding employment, exploring housing solutions, and developing friendships. In accordance with the principles of Independent Facilitation, the intention was to support the development of a plan and to implement concrete steps toward goal resolution, community involvement and belonging. Ultimately, a network of support meeting was to be held, engaging current and new network members to support the individual to plan for their future. The project was designed to demonstrate the varying needs of young adults with FASD and serve as the foundation to develop a replicable transition model. This initiative was put forward in response to a gap identified by Ontario FASD Workers and recent research.

A call for project participants was made and participants who responded and met the project criteria were accepted. A Social Provision Scale survey was administered before and after the project. At the end of the project, participants, parents, and professionals involved with, or referred to the project, were interviewed to assess the successes and possible improvements of the pilot project. This report draws on this data to evaluate this initiative and make recommendations regarding ongoing supports to young adults with FASD transitioning to adulthood.

### Rationale to Support Young Adults with FASD

There are currently very few support services for individuals with FASD. The transition to adulthood is especially difficult, as there are no individualized resources nor specific funding allotments in the province of Ontario. Because the FASD diagnosis is frequently misdiagnosed, or misunderstood, individuals with FASD are often blamed for making poor decisions or criminalized as a result of their disability. This lack of understanding implies that people with FASD are likely to experience situations of homelessness, mental illness, abuse, and criminalization. By providing support for creating community ties and reducing loneliness, the project also aimed to prevent crises, improve self-esteem, and build community capacity.

When alcohol is consumed during the pregnancy, there are permanent effects on the development of the fetus. It is estimated that 4% of the population have FASD (Flannigan, Unsworth, & Harding, 2018). A recent study among children of ages 7–9 in the Greater Toronto area estimates that the population-based prevalence rate is likely to range between 2 and 3% (Popova et al., 2019). The economic costs of FASD are estimated to be 1.8 billion dollars in Canada (Popova, Lange, Burd, & Rehm, 2016), with indirect costs

associated with morbidity and premature death, and direct costs in the health care, education, and justice systems. There are 428 comorbidities associated with FASD (Popova, Lange, Shield, et al., 2016). FASD is a lifelong whole-body disorder that affects memory, executive functioning, adaptive and social skills; symptoms can include dysmaturity, impulsivity, sensory issues. Diagnostics are complex and must be made by a multidisciplinary team (Cook et al., 2016).

This report will outline evidence for best practices, by comparing the literature on intervention, reviewing pre/post surveys, and through the thematic analysis of semi-structured interviews from participants of the project. By doing so, the report will make recommendations for the replication or adaptation of Independent Facilitation (i.e., customizing support for individuals in planning for self-determined goals and making community-based connections) as an innovative model of intervention to support people with FASD.

### New Literature on FASD-Specific Interventions

There is currently emerging literature on evidence-based interventions adapted to individuals with FASD (Coons-Harding, Azulai, & Mcfarlane, 2019; Paley & O'Connor, 2011; Pei, Kapasi, Kennedy, & Joly, 2019; Petrenko & Alto, 2017; Zarnegar, Hambrick, Perry, Azen, & Peterson, 2016). Early-childhood interventions focus on trauma and attachment, sensory regulation and social skills. There is little research on evidence-based interventions for teenagers and adults, although there is a crucial need. Payley and O'Connor (2011) state that "Interventions for people with FASD transitioning into adulthood are critical because substance use and abuse problems, high-risk sexual behaviour, and illegal activities may emerge or worsen during this developmental period." (2011, p. 72). Many guides and pilot projects have surfaced in Alberta, Manitoba, and British Columbia. Despite the many approaches, overarching values guide these targeted interventions.

The transition plan should: reflect the youth's vision and goals for the future; focus on the proactive shift from child to adult services; identify and build upon the youth's strengths and natural support systems; promote the youth's greatest level of independence possible and their inclusion within their community; promote self-determination; identify and address the youth's and their family's individual needs during the transition period; and prepare for necessary services and supports to be in place when the youth turns 18. (Coons-Harding et al., 2019, p. 2)

Interventions should always be early and follow a timeline. Collaboration between multiple stakeholders and the support of caregivers is also crucial. A multidimensional approach focuses on the individual's strengths and includes the voice of the youth in the decision-making process. Finally, a person-centred approach and proactive planning are all crucial factors to the success of an intervention. The guide "Toward Healthy Outcomes" (Pei et al., 2019) states three important characteristics for a FASD-conscious model of intervention: "1) a developmental lifespan perspective is necessary at all ages and stages;

2) interactive systems have additive and ongoing influences, and 3) our approaches must always be strength-based, empowered, and goal oriented.” (2019, p. 4)

### Independent Facilitation Among People with Disabilities

The Transition Coordinators’ role was based on Independent Facilitation, a practice that was developed to ensure that people with developmental disabilities and their families remained in control of the course of their lives and of the ways they receive support. The Ontario Independent Facilitation Network upholds many beliefs, including the rights of all people to set the pace and direction of change in their lives so that they will be included in their neighbourhoods and communities and have the same freedoms and responsibilities as any other citizen, as upheld by the United Nations Convention on the Rights of People Living with Disabilities, Article 19 (OIFN, 2020b). Independent Facilitation is a way to tailor supports and specialized services to individual needs and individual funding instead of adopting a one-size-fits-all approach (Bloomfield et al., 2000; Frazee, 1999; Lord, Kemp, & Dingwall, 2006). The tailored support enables a person with a disability to create and act upon their vision for a meaningful, ordinary life, based on a ‘community-first’ approach, where the community is the first resort in building a good life (Lord, Leavitt, & Dingwall, 2012) Independent Facilitators can support planning, the building of networks, and be a bridge between individuals with a disability, and community, natural supports, or more formal, occasional, specialized services.

The project management team and the Transition Coordinators were trained in Independent Facilitation and Person-Directed Planning, making the pilot project innovative in applying support resembling a supported decision-making type framework specifically to young adults with FASD. The project was proposed during the final year of the Independent Facilitation and Person-Directed Planning Demonstration project (OIFN, 2020a), with which the project management team and most Transition Coordinators were involved, having the same focus on the importance of genuine inclusion, belonging and raising people’s voices in the decisions that affect their lives. People with FASD do not qualify for provincially funded developmental services unless their intellectual quotient is documented in the developmentally-delayed range, but they do require daily support with regard more than one area, including social relations, employment, affordable housing or budgeting, to name a few. They also need support in articulating their goals, navigating services, and advocating for adequate supports tailored to their disability. The FASD community is unique in that regard, as the stigma associated with this disability is a moral one. Individuals with FASD, especially young adults, express strong desires to blend in or be treated like everyone else. Given the high risk of homelessness, incarceration or addictions among youth and adults with FASD (Carmichael-Olson, Rudo-Stern, & Gendler, 2011), the goal of this initiative was also to practise an individualized intervention and learn about Independent Facilitation as a desirable type of support for people with FASD after they become 18 years old.



## Methodology

### Participatory Research

#### Context

This pilot project was funded by the Ontario Trillium Foundation (OTF) as a Seed Grant Initiative and was implemented over the course of one year. After the internal structure was in place, recruitment of participants was made in both English and French, through ABLE2's social media, email and newsletters, as well as during the FASD Group of Ottawa meetings. Individuals with FASD were referred to the project manager by caregivers of youth with FASD, FASD Coordinators and other professionals from community settings. Of note, no individuals with FASD referred themselves. Voluntary participation, self-identification as an adult with FASD living in the Ottawa region, and being over 18 years old were the main recruiting criteria. A total of 15 individuals were accepted to participate in the project. Six referred youth declined the invitation to participate, three of which could not be reached or did not respond. Of the 15 who accepted, one dropped out because of court issues and another for health reasons.

#### Data Collection

Participants were asked to complete the pre-assessment social provision scale survey prior to beginning the project either in person or by phone. One participant did not due to a precarious home situation. Questions were inspired by Russell et al. (1984) and were administered orally in plain language. After support ended, eleven participants were invited to voluntarily participate in an evaluation interview and were offered a \$30 gift card for their participation. Two were not contacted due to their current situation of homelessness or abuse. Eight individuals responded; confidential interviews were conducted by Zoom or by phone, as per their preference. Three participants either did not show or did not respond to the invitation.

Interviewed participants were asked if they'd like to provide names of family members and professionals who were involved with their Transition Coordinator over the course of the project. Project management provided contact information of participants who were referred to the project but did not participate, which resulted in one interview. Additionally, interviews were conducted with two parents and two professionals from community-based organizations supporting participants. Finally, the project's staff was interviewed as well (i.e., the Program Manager, the Clinical Coordinator and three Transition Coordinators). Confidential interviews were recorded with Zoom and transcribed word for word, except in one case where the interviewee refused to be recorded (notes were written down instead). In total, 18 interviews were conducted (eight participants, three caregivers, two professionals, five staff). Themes were coded and interpreted with qualitative content analysis. Survey results, audio and video recordings and transcripts were saved on a secure server and data was anonymized for this report. Permission was granted by all participants to conduct interviews, record them, and make the results of this study public.

### Participant Demographics

Of the 15 participants, all spoke English as their first language; eight were females, and seven were males. Twelve were aged between 19 and 29, three were between 30 and 37 years old. Participants over the age of 30 were accepted to the project as there was not a sufficient number of referrals of youth within the project timeline. There were eleven individuals who were adopted, one who lived in foster care, and two grew up with biological parents (one was unknown); three who identified as LGBTQ (two were unknown, ten heterosexual); seven identified as aboriginal (two were unknown, six did not identify as aboriginal). Seven participants received confirmation of their FASD diagnosis (eight were suspected), and all participants had additional diagnoses to FASD (one physical, four developmental, two sensory, two health-related, and two had three or more diagnoses). The project did have the capacity to offer the support in French, but there were no Francophone referrals.

Participants mentioned a variety of situations prior to involvement in the project: eleven of them had mental health issues; five had addictions issues; four had justice-related issues; nine were on ODSP, one on Ontario Works, and two were employed; eight were living with their family, two in group homes, one in supported living, and two were living independently. They had more than one goal, but their main goals were in alignment with these situations, some of which included: six wanted to learn skills; two wanted to work on nurturing relationships; four on finding employment; three on volunteering; two on finding affordable housing; one on improving their mental health; one on finding leisure activities; one on fighting their addictions. It was interesting to note that most of the situations for participants over 30 years old were similar to those identified as young adults, for example, living with their parents or looking for meaningful social connections.

### Research Questions

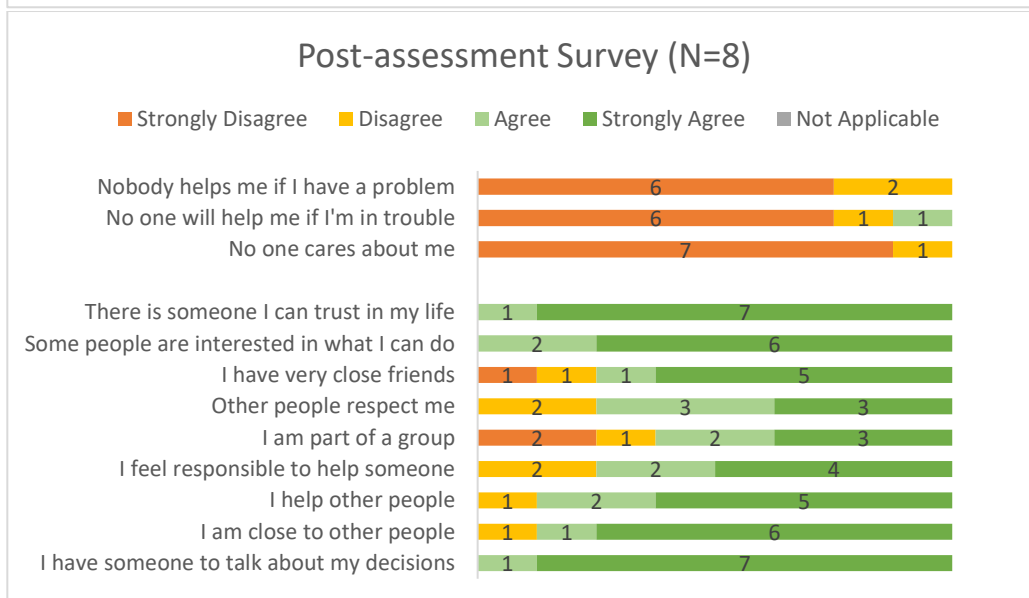
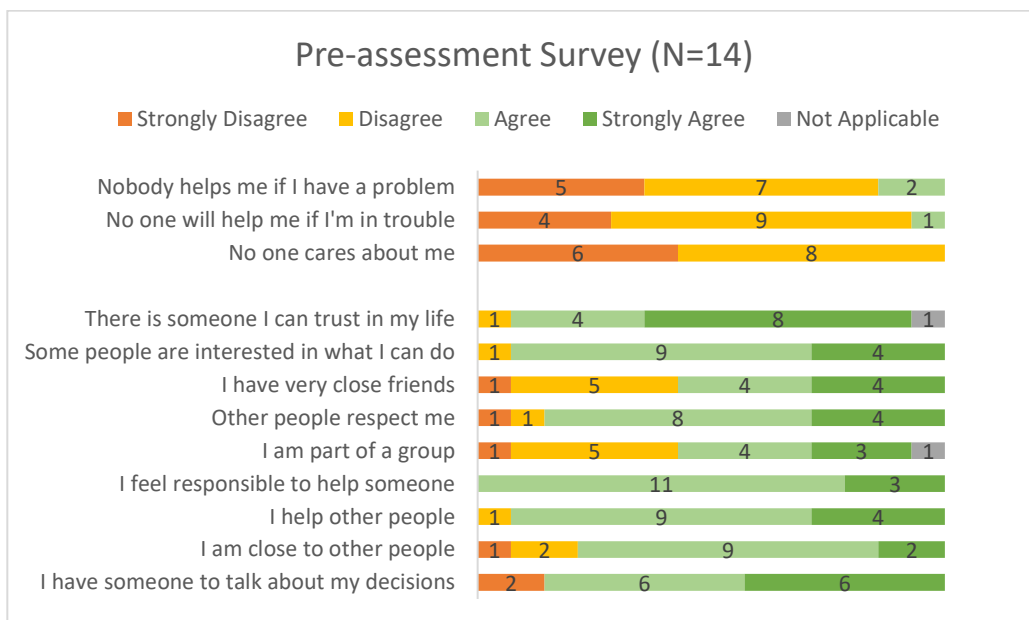
In the initial proposal, the key questions this project sought to answer were: 1) what are the distinct needs of individuals with FASD transitioning to adulthood; 2) what transition model can be used to best support this vulnerable population; 3) what types of interventions contribute to reducing social isolation/feelings of loneliness among young adults with FASD and improve their sense of self-esteem and belonging?

## Discussion

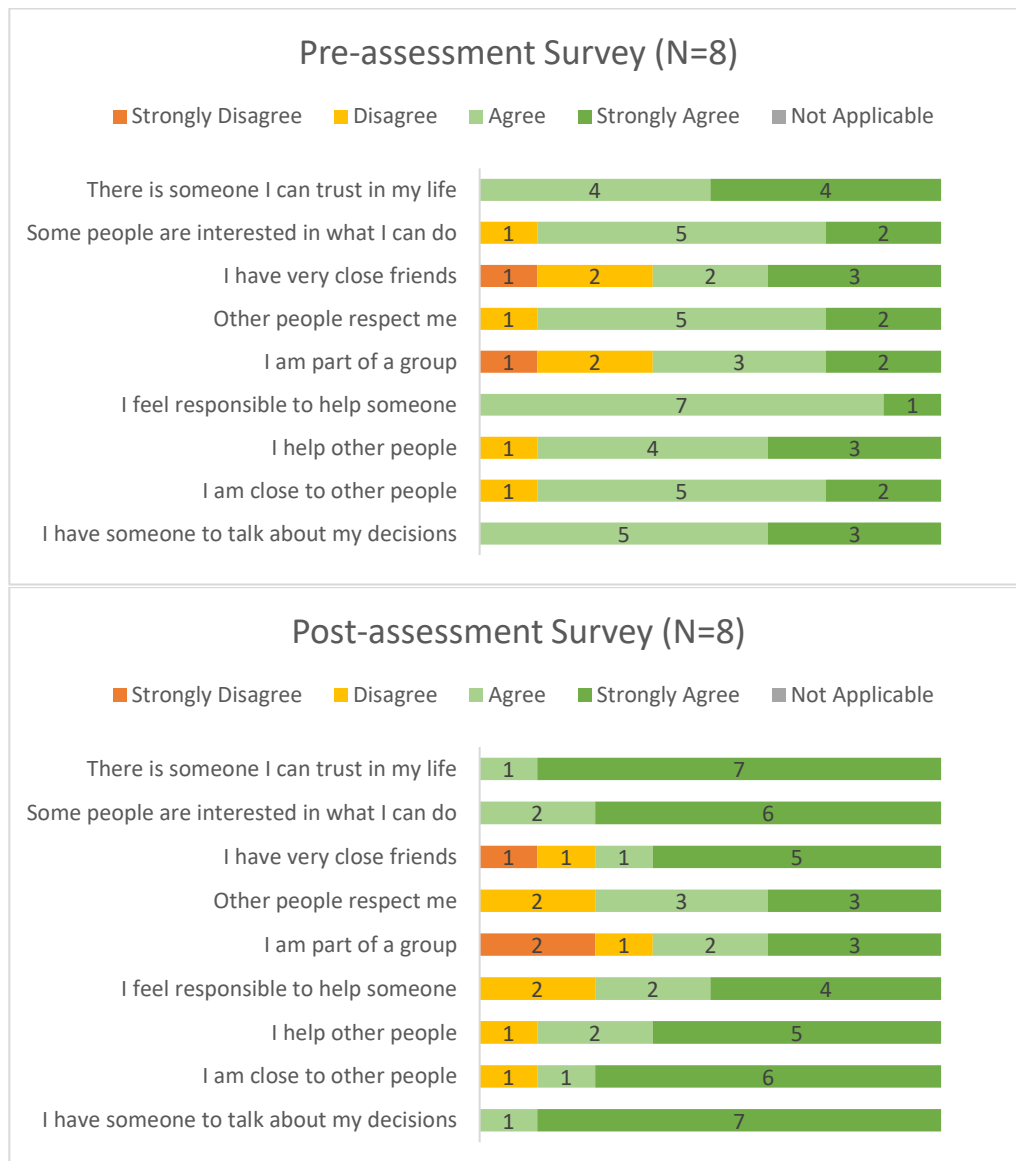
### Pre and Post Social Provision Scale Survey

#### Social Isolation & Feelings of Loneliness

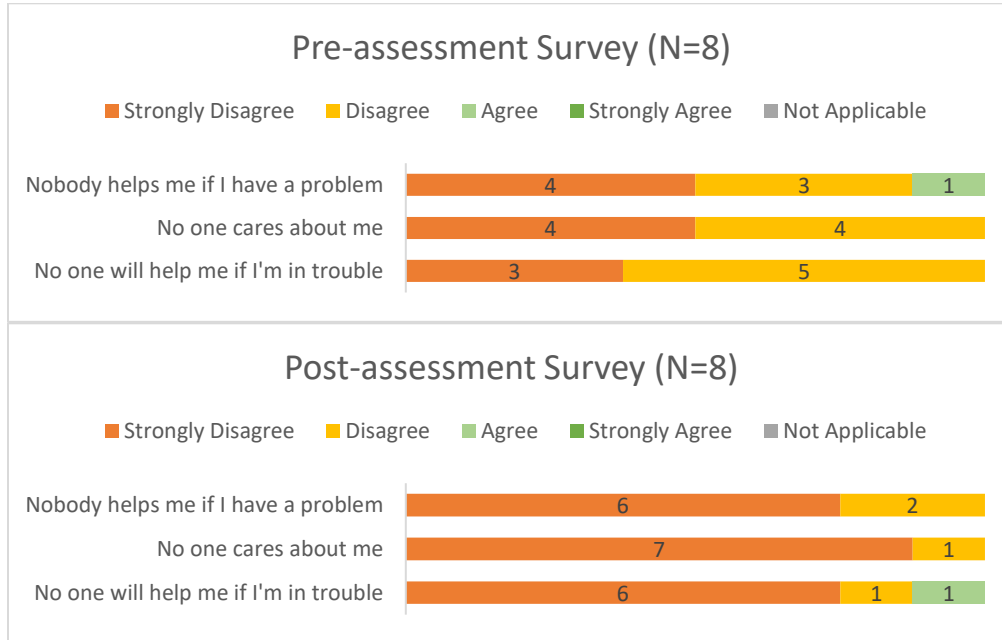
Overall results from the 14 pre-assessments completed between October 9 and November 12, 2019, indicate that individuals were not feeling overtly isolated in all aspects of the life before the project. Some participants were receiving support and felt that they could help people. Perceived isolation was fairly low, but real isolation was definitely present with at least six individuals out of 14 scoring negatively in specific questions. Most people felt like they had someone to talk to, and only two individuals of the sample did not. Many people with FASD did not feel they had very close friends and did not feel like that they belonged to a group.



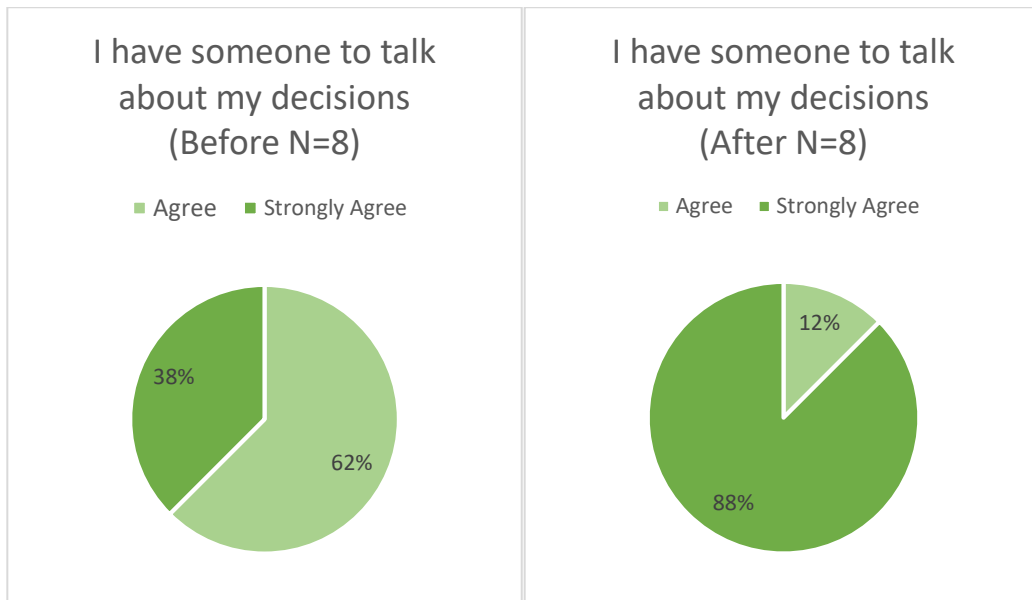
Comparative analysis of the same eight pre- and post-assessment surveys, completed 10 months apart, indicate that individuals felt more supported than prior to the project. Results above indicated that participants felt like some people were interested in what they could do (e.g., their goals and their strengths) and had someone they could trust. They felt that people cared about them. They also felt significantly closer to other people and had more friends. All the individuals that were still involved toward the end had someone to talk to about their decisions. When comparing data for the participants that completed the pre- and post-surveys, findings demonstrate unambiguously that those who completed the pilot project benefited from this experience (see the increase of responses from “Agree” to “Strongly Agree” before and after the project).



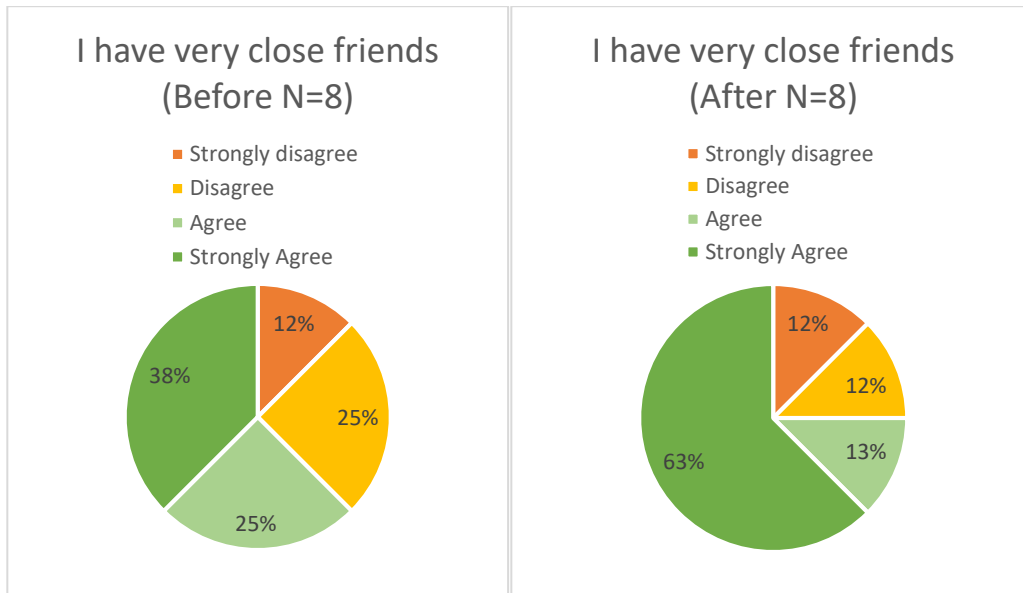
Similarly, participants who completed the pre- and post-surveys were less likely to be in a difficult situation as a result (see changes from “Disagree” to “Strongly Disagree” before and after the project). Individuals were feeling better supported if they had a problem or were getting in trouble; they were less vulnerable.



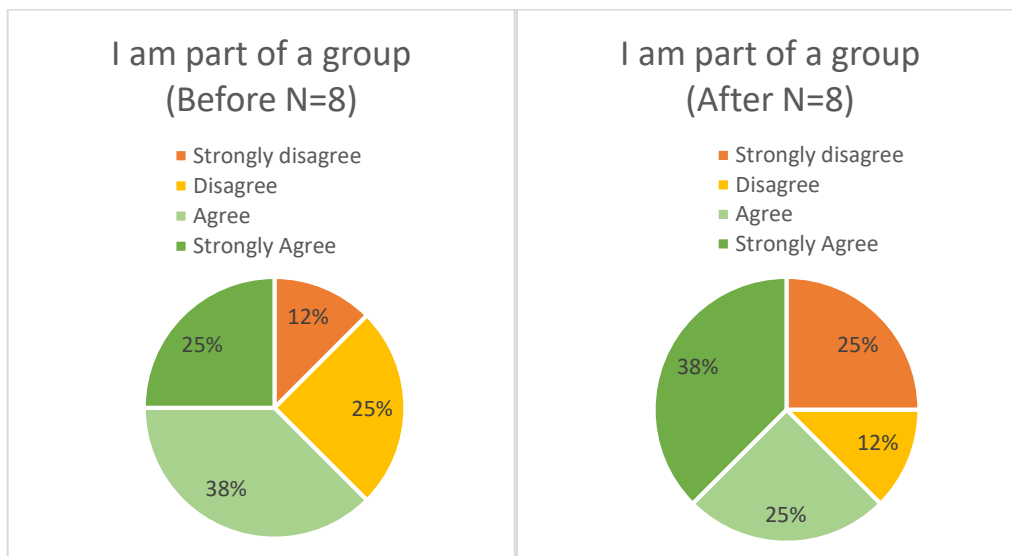
Among the most perceptible changes, the project was beneficial because it provided participants with someone to talk to about their decisions.



Another noticeable finding was that many felt they had more close friends after the project than prior to it.



Interestingly, toward the end of the project, some people were closer to others while some were more isolated; this can be explained as a result of physical distancing measures introduced because of the COVID-19 pandemic.



Overall, comparison between pre- and post-survey results for the same participants indicates that individuals were less isolated and feeling less lonely after the pilot project. In other words, they were more connected than prior to beginning the project. These outcomes may be attributed to the fact that Transition Coordinators were actively supporting individuals in planning for their goals: they met with them to listen to their hopes and dreams and connected them to other people through social networking and community organizations. The data set does not appear sufficient to establish conclusive grounds for evidence due to methodological limitations, such as small sampling and a low number of post-assessment surveys. Reasons underlying these changes in perception can be best explained with reference to accounts from participants about their experience of the pilot project.

## Semi-Structured Interviews

### Successes

Participants in the pilot project all expressed their satisfaction with this initiative and identified several benefits. First, this enabled some participants to make new friends and create connections. Participants expressed that they were supported for some of their identified goals, such as preparing for school, working on their employment and social skills, as well as addressing health issues with which they needed support.

In the process of planning for their individual goals, many participants claimed that the role of the Transition Coordinator was most helpful in supporting them to organize their thoughts and activities; individuals needed someone to listen to them, help them gain confidence, and motivate them to take action toward their goals. Talking to someone other than their parents or friends gave them perspective. They appreciated that these workers were able to understand them and their disability. They didn't feel judged. Finally, Transition Coordinators were utilized to support the individuals beyond their main role as community connectors: they coordinated support services with multiple agencies; they kept individuals accountable to their self-determined tasks; they were engaged in conflict resolution between family members and at the workplace.

Six of the eight individuals interviewed claimed to be more connected: "Huh, yeah. I feel like I reach out to a lot more people now." Two participants did not feel they were more connected, but this doesn't mean that they did not benefit from working with a Transition Coordinator. As one participant stated: "Hum. I'd say I get out more now. I don't know about more people in my life, but I don't... I'm not as a recluse. I don't know if that's the word I meant." Loneliness was explicitly addressed as a major challenge during the interviews. Though participants did not always succeed in establishing new connections, Transition Coordinators supported them to plan and practise to do so.

"Before, I was really, really isolated and I didn't have really anyone to talk to. And just those meetings with (the Transition Coordinator) were a boost. Me and her, we really got along. And she has a way of being silly and fun; but at the same time,

eventually you got to the point, and things got done. So, I thought that was really cool. And we still talk, so... It really helped. Yeah.” —Youth with FASD

For example, one participant claimed that the project made a difference in her life, as she did not feel confident in tackling adult life by herself. She explained that she saw a big difference between her high school and college, where nobody takes attendance.

“Yeah, I’d say so, it definitely made a difference in my life because I was like very, very new to college and as like a young person with FASD, like with other disabilities, (University) was and can be scary, so even though I got to go at it, it definitely helped to meet with somebody and talk, and just like, the thought process, going through everything really helped. So, it definitely helped and stuff.” —Youth with FASD

Working on self-determined goals may imply that skills be acquired first to achieve them, such as being organized, knowing how to socialize or manage one’s finances. Goals included tasks such as going to see the doctor or getting a driver’s licence. These examples relate to the usual challenges of becoming an adult, although the timeline might be extended for a young adult with FASD.

“But yeah, one of the goals was like saving up for a car. I’m almost there! I’m really excited. Because like we worked out this whole plan, like what goes in my chequing account, what goes in my saving account. What goes what... Yeah! (She does a ‘thumbs up’.) It was great. I’d say that one of the major goals that I had, and I think it’s the only one we worked out an actual step-by-step plan for, but it’s working.” —Youth with FASD

Individuals with FASD often feel like their disability is not understood and having someone trained prior to their involvement with them was a definite prerequisite for success. The need to have a sense of closeness, friendly communications, and careful matching of the individual and the Transition Coordinator were some positive elements that were mentioned several times during the interviews.

“Like, it’s like, if I’m talking to this Coordinator and I’m explaining to her about my FASD and my disability, I definitely don’t want it to be an awkward thing. I want it to be the kind of person I would go for an ice cream with or something. Yeah. So, she did a good job.” —Youth with FASD

Because of their complex needs and personal and family histories, individuals with FASD often have worked with several professionals throughout the lives: psychotherapists, social workers, occupational therapists, probation officers, etc. Yet, none of them address their personal needs in the same way that a Transition Coordinator could in the context of the project. One participant claims that it is because of the individualized and symmetrical relationship between worker and individual: “Because they understand.



They work one-on-one with you, so they understand more than when you have five different workers working on the same caseload.” Relationship building is crucial to fuel individual engagement and persistence in the process of planning for one’s future.

The two parents interviewed, mentioned that they appreciated having more supports around them: “Well, she... It was just another person in our lives, you know, that was listening to her (my daughter) and that could help her to huh, you know, think through some of her thoughts. Determine her goals, so. Yup.” Transition Coordinators were seen as invaluable because they have ideas, resources, and connections that parents do not necessarily have. Finally, because of the challenges of this disability, many caregivers suggested that they are tired and exhausted, and that the involvement of a Transition Coordinator was seen as an opportunity for them to take a step back in their adult child’s life. Unlike FASD Workers who intervene at the family level with children and youth in Ontario (up to age 18 and 21 if still in school), Transition Coordinators are professionals that often provide information and emotional support to the adult directly. They also provide support to parents and caregivers indirectly.

“Well, somebody else in the same position that we are in, you know, aging and worrying about the future. And knowing that there isn’t much out there, we know this, we are fully aware. So, Transition Coordinators help, they have more contacts, they have more ideas. Somebody other than me having ideas is good too, you know. That doesn’t mean that everything that I think is correct for her. So, I also like somebody else to talk it over with.” —Parent of a Youth with FASD

Professionals from community organizations interviewed mentioned that they were looking forward to collaboration with other agencies to better support individuals with disabilities. They felt that this collaboration was fruitful because they shared values about the rights and capacities of the focus person. Transition Coordinators brought several partners around the same table for meetings. It was expressed that this practice should happen more often.

ABLE2 staff who were interviewed mentioned that they appreciated how the project was structured and organized. Communication from management was very clear. They perceived the flexibility of the program as one of its major strengths. Staff felt they make a difference in several areas of the individual’s lives, including housing, finances, schooling. They perceived their role to have the most impact on the individuals’ confidence and self-esteem. Project management identified rapport between participant and Transition Coordinators as a success, as well as the fact that there was a good retention of participants throughout the process. Management explained that this pilot project was perceived within the organization as a positive step for continued capacity building to supporting adults with FASD.

## SUCCESS STORY: FINDING EMERGENCY HOUSING

“A younger adult was living on the streets during COVID, and really at high risk. And the Transition Coordinator was able to work with the young person and his family and his probation officer to find multiple placements for him to go throughout the last few months. So, there wasn’t success in finding him a stable place to live, but there was a success in finding him multiple temporarily places, safe places to live where he wouldn’t be on the streets during COVID. So, I think, in that sense, that wouldn’t have happened if he didn’t have a Transition Coordinator, he would have been on the streets. So, in terms of keeping him safe, and getting him services even though they were only temporary, the Coordinator played a key role in that, without a doubt. So, at that level, there was success, but on the systemic level, there wasn’t success, because there is no housing for our people. And that’s not the fault of the youth looking for housing or of the Coordinator trying to help him find housing. It’s a systemic issue. But I really believe that the Coordinator made a difference in the last three months in this kid’s life, since COVID hit in March. He was literally sleeping behind a dumpster, and we were able to, with the Coordinator’s help, to get him into detox, we were able to get him into some temporary hotels where he would be safe and warm. We were able to get him food while he was in those hotels. So totally successful in that way. That’s just one example.” —STAFF





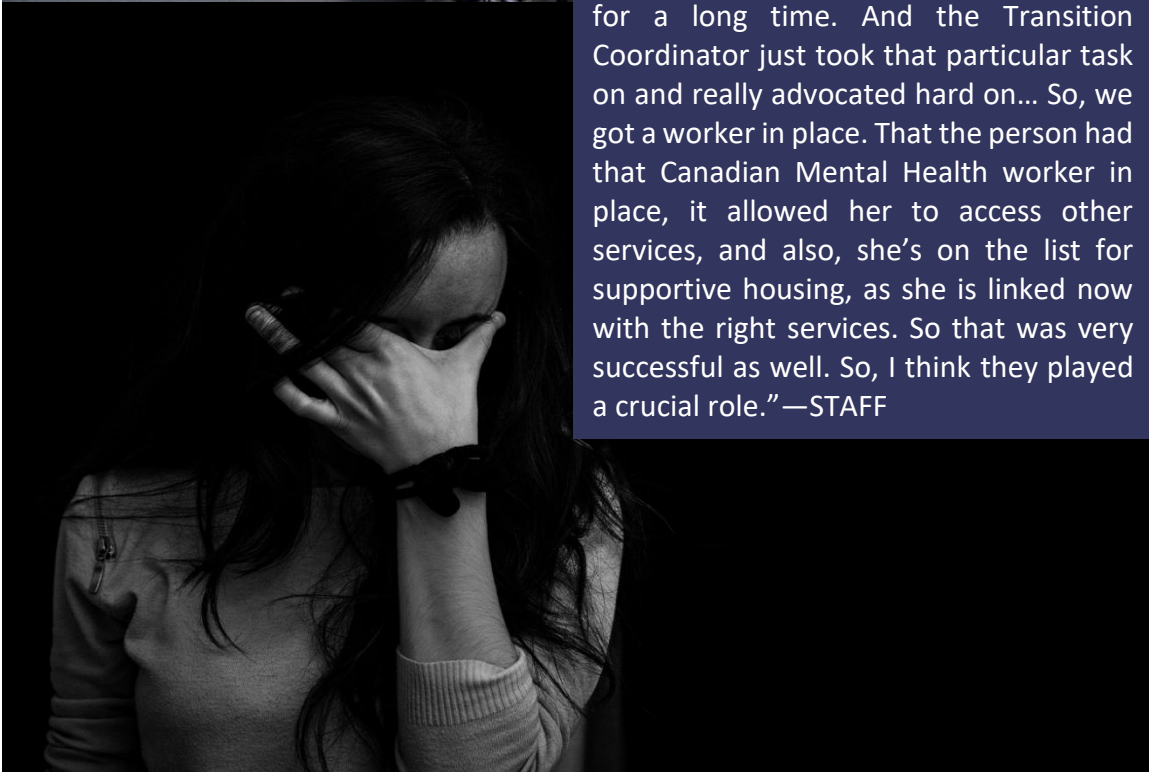
## SUCCESS STORY: GETTING A HEALTH CARD

“One individual has been saying that she wanted to get a health card for two or three years. And we talked about it at our first meeting. We talked about it at the second meeting. At the third meeting, I said, well you know, we looked at the location, we looked at what she needed to bring. And I said: ‘OK, so you know, text me when you do it! It’ll be ‘Woohoo!’ and we’ll celebrate.’ It wasn’t done. So, the next meeting, I said: ‘Why hasn’t been done?’ And she said: ‘Well, I don’t know, I don’t want to go there, and they are gonna think that I’m stupid because I hadn’t had one in for so long.’ So, I actually drove her there. ‘Well, you know, we got time now, why don’t we go now?’ And she was so excited. She went to get dressed and came downstairs. So, it was just, you know, not judging her by saying, ‘Well you should have done that. Why haven’t you done it by now?’ It’s just, “Well let’s go do it now.’ And she got it! So, you know, that was her first goal. Check. But you know, after that, she was excited that she was able to get referrals for things that we had lots of concerns about. So, that’s just an example, you know, of that.” —STAFF



## SUCCESS STORY: CONNECTING TO THE CANADIAN MENTAL HEALTH ASSOCIATION

“There were a lot of successes with another Transition Coordinator who was able to finally link the young person with the Canadian Mental Health Association. Because we have been trying to link her to the Canadian Mental Health Association for a long time. And the Transition Coordinator just took that particular task on and really advocated hard on... So, we got a worker in place. That the person had that Canadian Mental Health worker in place, it allowed her to access other services, and also, she’s on the list for supportive housing, as she is linked now with the right services. So that was very successful as well. So, I think they played a crucial role.”—STAFF





## SUCCESS STORY: GETTING AN INDIAN STATUS CARD

“There are so many things or so many barriers that come before having a job or getting into a program. And one example that I’m thinking of is someone I was working with who has a First Nations background. And her Indian status card has been expired for... I think it was like 2004. And although some of her goals were to go to school or to get a job and make money, things like that, not having this card and not having that recognition was very difficult for her. Anxiety, her confidence... It also closed doors in terms of opportunities that having a status card could have in terms of education, and work possibilities. So, we... To me, it was very simple to figure out what we need to gain access and get her status card. And then we spent a day and got it done. It was a day of my time, but for her that meant the world to her. And it was something that no one had supported her with since 2004. And I feel that she’s been in the system, she’s been in many programs, and they are all very constrained and have boxes, but the freedom that we had in this program, flexibility and accompaniment, meant that we could solve this problem for her. And once that solution is there, things like the confidence can happen. Which then lead to other things, or other opportunities that can come about.”

—STAFF



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|  | Registration no./Numéro d'inscription<br><b>916700185</b>                              | Family Name/Nom de famille<br><b>DOE</b>           |
|   | Date of Birth/Date de naissance<br><b>1958/07/15</b>                                   | Sex/Sexe<br><b>F</b>                               |
|   | Date of Issue/Date de délivrance<br><b>2009/05/11</b>                                  | Renew Before/Renouveler avant<br><b>2014/05/11</b> |
|   | Registry Group no. and Name/N° du groupe de registre et nom<br><b>3456 - BAND NAME</b> |  |
|   |     | Given Names/Prénoms<br><b>JANE</b>                 |
|   |     | Alias/Nom d'emprunt<br><b>ANNIE</b>                |

## Improvements

Participants to the pilot project did not mention many improvements to the initiative other than one participant explaining that sensory issues should be considered when choosing a location to meet. Individuals with FASD often have ADHD or sensory issues which can make it very difficult for them to focus during a meeting, especially in public places.

“I get distracted by food very easily. Also, I’m the kind of person who, the second there is some motion in my peripherals, I’m like ‘hummm???’ I HAVE TO look. So, we got distracted A LOT. So maybe a place where there are no cars driving by? Or maybe just not sit next to a window. Maybe no coffee and donuts for distraction.” —Youth with FASD

The location of the meeting was important: some young adults did not want their parents to be present when they were meeting with their Transition Coordinator. Some participants did not have access to the internet and relied on coffee shops to have access to free Wi-Fi. One participant’s apartment was infested with pests and his house was a safety hazard. COVID-19 confinement measures meant that meeting in person and community connections were impossible, which put a strain on relationships and goals.

Moreover, another participant mentioned having better timelines when planning for goals to ensure things are moving forward. “I would set a timeline. We start this on this day, we end it on that.” He stated that he did not fully realize the potential that meeting with a Transition Coordinator meant to him, with respect to achieving his goals by himself.

One parent, who did not want to be involved at first, expressed regret toward the end of the project that she did not participate more in the process of planning.

“Hum, well, like I said, I don’t know if initially they were supposed to talk with parents, just to discuss their child or not, and I sort of took myself out of all of that. So, I don’t know if that was one of their goals. But that’s what I would recommend, that they did.” —Parent of a Youth with FASD

Parents mentioned that the pilot project was constrained due to time limitations, and that the nature of the disability made it unlikely to achieve significant changes in a short period of time. One parent stressed that the project should be significantly longer, as some goals can be reached fairly, but that these accomplishments may require additional help to be sustained overtime.

“Just that, that it’d be great, it is a great thing to do, it is a wonderful thing for our kids to have somebody help them and reach out to do all of this with them. But I’ll still say: it has to be long-term. It can’t be stopped. Because we know it takes longer for them to gain employment and keep employment. And, you know, it

could take years! (Laughs) And, the parents, we are tired.” —Parent of a Youth with FASD

Families often see professionals coming in and out of their circles, but they feel that they themselves cumulate several roles in addition to being parents. One mother stated that she finds it cumbersome to act like “the mom, the advocate and the educator” all at once.

It is worth noting the number of parents who referred their child to the pilot project, who, in turn refused to participate. One such parent believes this is related to her sons’ anxiety issues, as well as the fear of becoming an adult.

‘Well, he just... That would be one of the reasons why he didn’t want to join. I think another is that he would actually be petrified that this would lead to something like a job. And often, he has had tremendous anxiety issues, but now I would say paralyzing anxiety. So I think that’s probably one of the things was that this person might actually be successful in connecting him to something, and he was really scared to do it, and when he thinks he actually wants something in his life, when you try to put more things in his life, he panics. That’s when we start to see a lot of negative behaviours, to the point where we say, “OK, let’s go back to what was working.”’ —Parent of a Youth with FASD

As for staff, project management and Transition Coordinators all mentioned that the initial contact is a crucial moment to approach individuals with FASD and obtain their engagement. Because individuals with FASD often need help with organization and struggle with executive functioning, persistence in communicating with them is necessary. Gaining trust in an outsider may require time and gentle persistence.

“They might want the help, but because sometimes they are difficult to reach, have memory issues, that sort of thing, once I reached them on the phone, it was: ‘Oh, I’m glad you persisted to reach me. I’m glad you did that, because I do want the support.’ So yeah, I would say that it’s the communication and the contact.” —Staff

For this reason, some individuals were reached in the phone, and others were met in the context of an event they were attending at the time of participant recruitment. A blend of contacting participants through the phone and in person appeared to work well.

Since pilot projects are time-limited, they often require significant investments in time and resources to set up. This means that forms must be created, process and structure must be put into place before the actual work can begin.

“Well, just at the beginning, there were bumps because it was new. So, things were being set up, so there was confusion at first. But once we got things rolling in terms of, you know, forms being made and expectations being clearer... It was

mostly the admin side that was being tricky at first. But when you are setting things up, that takes time. That's perfectly fine. Improved in terms of... The only thing that could have been improved upon is... I think it's been rectified!" —Staff

Another staff said there needs to be a clearer structure in place to support individuals: "Hum, I think in terms of connection with a facilitator/transition coordinator, the individual and the organization, that triangle I think could have been stronger." Expectations and communication between stakeholders more specifically for youth between 18 and 21 years sometimes led to confusion, as many professionals working in the field of disability are not familiar with Independent Facilitation and person-directed planning.

Along those lines, staff mentioned role clarification as the second biggest challenge. Transition Coordinator roles were often confused with case workers, social workers, or support workers, and may in fact overlap at times, for example when facilitating communication between different persons and community partners to support an individual in achieving their goals.

"Maybe bit of clarity with of our roles from the onset. As the project went along, before COVID-19, it wasn't clear what my role was as opposed to the other person who was ... had this individual on the caseload. And it took a while before that was cleared up, because I was working in a certain way... We weren't working together. But eventually we got the roles cleared up and we went on." —Staff

Another example is a parent who had assumed that the Transition Coordinator was offering employment support to her son, just like other service providers do. In that regard, there is a risk that independent facilitation duplicates existing services, especially given service scarcity and long wait lists to access programs and social supports in Ontario. They build good rapports that other professionals would need to replicate before making progress with the individual and their families.

Staff all felt that individuals with complex cases require additional support, more time and resources, and some sort of clinical expertise and support. They expressed concerns about the limited framework of the project. The support provided to individuals with FASD was much needed, but for the participants with complex needs, it felt as if they only grazed the surface, focusing on basic needs that were not met, rather than reducing social isolation and feelings of loneliness.

"So, if I could, if I had a magic wand, that would be great if they could have, you know, more hours where workers would be available. (...) More time, more money, and more flexibility in being able to reach out to these kids is what is needed, for sure." —Staff



One staff expressed that the nature of the work requires significant knowledge and emotional investment and may not necessarily be suited to contract positions.

“Like, I don’t know if it’s best suited for a contract position because it may mean getting calls at 11 p.m. And then, or it may mean suddenly all these emails while you’re on a road trip (laughs). I don’t know, I think a position where it was a full-time position, working with this group so there is that flexibility... Otherwise, it’s very sporadic times, and it can be crisis situations too. So, it’s not too easy to get a call at 11 p.m. that someone is in a victim’s housing unit and that they are homeless. What do you do? That’s not easy. That takes time to process and outside of the work you are doing with them. So, I think that in a full-time position, there is a whole other feeling about it, whereas as a contractor, I don’t know if that’s the best fit.” —Staff

This reflection brings to the light the full-time support (i.e., 24 hours a day/7 days a week) that is often required by a youth with FASD. Even when defined by a full-time position, parameters that limit the support hours from 9 a.m. to 5 p.m. on weekdays, for example, will not be suited to effectively support individuals with FASD. The Transition Coordinators were aware that responding to urgent or anxiety-provoking situations immediately would most likely result in avoiding the crisis altogether.

In summary, interviews with the parents, community professionals and staff revealed that the project presented significant challenges in establishing trust and confidence for some individuals within a short period of time; achieving self-determined goals that necessitate additional supports for meeting basic needs or sustaining accomplishments for individuals with complex needs; working around complex problems with limited time and resources. Finding a balance between flexibility and structure was difficult for some staff, as there are often communication challenges in working with Individuals who have FASD, and limited resources and supports for workers to rely upon when problem-solving sometimes extreme situations. The ambition of the project within the limited timeframe was a challenge, in addition to the imposed public health measures facing the pandemic. Even so, it can be said that an integrative and collaborative approach encompasses all stages of an individual’s life within an ecosystem of friends and caregivers, health and mental health service providers, and community partners. It takes into account each individual’s developmental stage and psychosocial challenges. Such an approach is best suited to provide ongoing and timely supports geared for the specific disability that is FASD.

## Impact of COVID-19

Because of the COVID-19 pandemic, many of the goals identified by the individuals at the onset of the project could not be achieved. Some goals were stalled temporarily, and some were definitely stopped. Placements in the community were interrupted, as some organizations decided to no longer take volunteers, for example. Some individuals who were previously isolated became even more so, due to imposed public health measures. Face-to-face contacts were prohibited as of March 16, 2020, at a phase of the project when meaningful in-person social relationships and connections were being established. Participants who had access to technology were in a better position to stay connected with their support network and Transition Coordinator.

Access to technology and Wi-Fi enabled participants to remain connected through videoconferencing, texting and phone calls. It also enabled frequent check-in contacts, and virtual gatherings with the FASD youth group, which was very much appreciated, and enabled new friendships to bloom between participants of the pilot project. It appears that goals changed; even though creating friendships with other individuals with FASD is valuable, it was not an official goal of this project. One could argue that connections were made at a time when these were extremely difficult under the state of emergency.

- Huh I think I have achieved most of the goals, yes.
- Even with COVID-19?
- Even with COVID.
- Oh, that's great. And how would you say you were supported in achieving these goals during COVID?
- Huh, just through Zoom and talking.

Some participants were not as enthusiastic, as they felt an opportunity to improve their life was taken away.

- Plus... To be honest, I kinda got screwed over by COVID. But...
- OK. How was it affecting you, COVID-19?
- Well, because we were looking into getting a job, but when they called me, that kinda went out the window.

Many goals could not be achieved due to the pandemic, including, for example: launching a business, scheduling doctor appointments and socializing with new people. One participant deplored the fact that she could not volunteer with animals. "The Humane Society is something that I really wanted to do, but unfortunately, when the pandemic started, they stopped taking volunteers." In one case, a participant had to postpone her dream to learn how to fight with a sword, which she read about instead.

"Well, it didn't affect, well, you know, being with my Transition Coordinator, because you know, we chatted on Messenger. But like it affected me in reaching my goals because, you know, how are you supposed to learn how to sword fight if

you're six feet away? Or, you know, I discovered my ancestries had connections to the most ancient noble families in Normandie, so I wanted to learn European-style sword fighting and archery and stuff." —Youth with FASD

For this participant, the COVID-19 pandemic enabled her to be creative: with the help of her Transition Coordinator, she gathered the courage to post fan fiction online.

- I completed a diploma in Japanese language and script online. And I actually started to, actually posting my fan fiction online. And they are doing REALLY well.
- Wow.
- Yeah! And because of COVID-19, I went from a few hundred readers to THOUSANDS. So, gosh! So much work. Because you know, if you don't post when you say you post, they have a RIOT. Like responding to over ten thousand comments, every day, is a pain in the butt.
- It's a lot of work, huh?
- Yeah but in the end, it's so worth it because people are actually enjoying something I made. It just feels really good. It was because... I was able to get over, you know, my anxiety and actually post it.

One Transition Coordinator arranged for a physically distanced meeting with an individual when public health measures allowed to do so, toward the end of the project. The capacity and importance of in-person meetings are fundamental to the work of Independent Facilitation, as the human connection is crucial to getting to know the person, inspire a vision, mentor them to explore and direct their support. There are also limitations in not being able to access basic services, go to places, or gather with people whose relationship is damaged or precarious.

"I would say that a lot of the work that is done through facilitation is in-person. So, it's going with the person to the Housing Registry. Going to do some type of community organization to help them, make sure the contact is well established, and that they understand, for example, where to access that resource. Or if it's... I mentioned earlier on, people with whom a relationship was established. There was a young man, a relationship was established with his dad. There are people who wanted some support to visit their children, for example. So, it's a lot of in-person... Absolutely, those goals were put aside as soon as the COVID-19 hit. Yeah." —Staff

COVID-19 was a professional challenge to the Transition Coordinators as they were invested in making a difference in the life of the people they were supporting. The pandemic challenged conventional methods of supporting the individuals: Transition Coordinators could no longer connect the individuals to informal and formal community services; they could not explore new options. It was not always possible to imagine new goals to be achieved during times of crisis, albeit some did. Moreover, Transition

Coordinators were not hired as counsellors, so they could provide only limited support to individuals and caregivers experiencing high anxiety linked to the pandemic.

“Well, I guess I’ll put the pandemic and whatever came out of it, that kind of modified whatever expectation I had of the project. Because one of the strengths of this project was to have physical contact and meet with people who have FASD and engage in a relationship and support them in whatever they were requiring. The fact that we weren’t able to do that... Maybe the project wasn’t successful, but within the FASD project, I kind of was able to do with whatever confinement came out of COVID-19... It could be OK, but as a community connector, it was actually extremely challenging. And personally, it’s how ... all my work I do, it’s physical and human contact.” —Staff

COVID-19 was a time of anxiety and distress for many participants who could not handle simultaneously the fear of the epidemic and the stress of planning for their future. One professional recalled: “I had one individual, when COVID-19 happened, they just said: ‘I’m signing out!’ and I didn’t hear from them anymore. (Laughs)” A parent, speaking in a similar fashion, declared they were making progress, “Yeah, until COVID-19 happened, of course, and then everything stopped. The world stopped.” In cases where there was no significant progress, individuals and parents blame the confinement measures rather than the pilot project’s design. They remain hopeful that the initiative would have made improvements in their lives in different circumstances.

- Do you feel your child has more people in their life in comparison to before they started the project?
- Well, no because, you know, we are in lockdown, so. And I’m sure that because of that, it would have moved a bit more if we weren’t isolated.

Given these extraordinary circumstances, the success and limits of this pilot project are strongly mitigated by factors that were independent of the participants and the Transition Coordinators. For that reason, in-person circle of supports as intended could not be completed, although this was an explicit goal in the funding application for the pilot project. In response to the announcement of confinement measures in Ontario, management successfully donated electronic devices to participants to help them remain connected. Laptops and phones with a prepaid data plans were provided. One individual even received two phones, as he broke his first one. Unfortunately, staff still could not reach him; they presume he lost or stole the second one in exchange for food or drugs. Still, it was important to staff to provide that individual with technology to ensure he had an equal opportunity as everyone else, and that he was “given a chance” like the other participants.

## Supporting Individuals with FASD

When interviewed about the best way to support individuals with FASD, participants, parents and professionals provided similar answers. Young adults insisted that the best support is void of assumptions that others know better than what the participants themselves need; that their choices are respected, and they are listened to; that they be treated as individuals, with everyone approached distinctly and considered as different. They expressed a need to be understood, not judged. They feel that workers who come into their lives should be informed about FASD and slow things down for them; they could be provided with reminders, without talking down to them. They want a worker whom they can relate to, who is friendly and compassionate. One individual with FASD makes it clear that she wants her goals to be self-determined:

“If some of the people have a goal of, let’s say, be a pole dancer, they should have the people that help them to get to that goal. And if other people have goals like ‘I want to become a nurse’ or ‘I want to become a scientist’ or ‘I want to become a *whatever*,’ the coordinator should be individualized and personalize toward each individual, instead of assuming that they each want the same exact thing.”  
—Youth with FASD

Stigma is a major obstacle to individuals with FASD getting recognition and support for their disability. As one participant puts it, having a good attitude is more important than knowledge: “Honestly, I think it’s just like, listen and understand, and like not be afraid. Because FASD is not like an STD, you’re not gonna catch it.”

“Try not to be condescending, but it’s like, there just have been people, of course, you are scared of what you don’t know, but a friend who doesn’t mean any harm, but they’ll just act like I’m the dumbest person in the room because of FASD, so if they’re gonna think this, I’m just gonna act like the dumbest person in the room. That was my coping mechanism where I... I don’t know if that’s really a coping way.” —Youth with FASD

It is important that workers treat people with FASD like a human being, and that they talk to them like everyone else. One youth was clear about her negative experience regarding the tendency that workers and friends may have to patronize her. “Oh yeah... Here’s something: not talking to somebody like they are an injured bird. I HATE IT when people talk to me like I’m an injured bird or something.”

Caregivers indicated that workers must be persistent with communications and reminders, as individuals sometimes forget or lack motivation to follow through with tasks or appointments. “They need the consistency of somebody to follow through with them in a job, and when that doesn’t work out, go through for the next one, for the next one, because they always need that support person.” Working with someone who has FASD means to never give up and keep trying repeatedly.

Other feedback from participants included that workers should have good organization skills in addition to understanding the nature of the disability. One parent insists on the need to keep track of goals, steps, and tasks: “You have to be somebody else’s brain, so you have to understand that.” This parent of an individual with FASD recommended that caregivers be involved prior to service delivery in order to provide personal history and advice, to know what has been tried or not, and what works or does not. Parents recommend erring on the side of caution when initiating new projects or suggesting ideas to their child, as they feel that their child may be especially vulnerable in new contexts or settings. They recommend a holistic approach that does a frequent analysis of their child’s strengths, as these strengths are likely to vary over time. One parent whose child did not participate to the study deplores the difficulty to get new parties involved in improving family dynamics, especially when individuals are caught in abusive relationships.

“I was hoping that he would at least discuss and make a plan for this sort of part-time employment, or at least applying for employment. Perhaps some assistance with looking at different possibilities. Maybe some sort of coaching with interviewing. Those sorts of things, but huh, so he was actually in a very vulnerable situation at that time, so he was in a relationship with somebody, or just finished a relationship with somebody who was very abusive to him. And he wasn’t yet over it, he wasn’t moving on. I was also hoping that someone outside our family would give him a more objective sounding board as to what would be good to him, and that he deserves to be with somebody who is better, and help him make a plan for being able to meet other people, not necessarily for a relationship, but for friendships. To just put some positive people in their life so that he wouldn’t be as isolated, as we were worried that he would run back to that person if he was too isolated.” —Parent of a Youth with FASD

As for Transition Coordinators, they expressed that the best support must be consistent, respectful of the individual, and use positive messaging. Good support involves an equilibrium between being very structured and flexible. Coordinators have to “delicately persist” in order to move things forward, as one staff puts it: “You know, delicately persist, if I can say it that way? I’m thinking of the individual who said, ‘Thanks for reaching out to me. I had problems with my phone, and you know, ta-da-da.’” Frequent check-in contacts by the worker are necessary. There might be missed appointments, but this does not mean the individual does not want to follow through. One cannot assume that things will be done if the right information is provided to the right party. This is about “not just giving them resources but being their anchor with them.” This is exemplified during times of crisis.

“There has to be ongoing one-to-one and fairly intensive casework happening on a regular basis. And I think we need to be able to continue our services well into their adult lives, that we can’t just transition them and say: “Here, we got you on the wait list for housing, we got you on ODSP, you’re talking a course, and now

you're all set! You're an adult now." That's just absolutely ridiculous. So, we need to have ongoing support and services for our adult clients who have FASD for life. It's a lifelong brain injury. So kinda setting them up: "OK, you are all linked and now you are done, no more support for you...", it's ridiculous because they will fall, without ongoing support. So, for sure, ongoing counselling, ongoing practical interventions to help them into day-to-day functions, well into their adult years." —Staff

Because of their relationship with individuals, Transition Coordinators, unlike case managers, social or support workers, must act like a translator between the individual and the service providers. They contributed to building capacity in the system, not only by modelling formal service providers on how to support individuals with FASD, but also contributed to reframing the criteria of eligibility to accommodate individual needs. One Transition Coordinator made that distinction very clear in the way he approached his role:

"So, my overall picture of this is that it's very important to accept that there is nothing, and you cannot necessarily create a FASD line of service for... So, the idea is that our line of work has to be some sort of brokering or negotiating with existing services and to see if the people who have FASD, when they get into the after-18 world, they... It's not necessary to knock on the doors and be 'OK, would you accept this FASD person?' It's mostly to go pick parts of different supports and see if they could help and wrap around an individual as opposed to expect a service provider to be able to understand the complexities, as we are actually learning the complexities from the young adult falling into the adult support system, which is very limited. But I've had a little bit of success in at least opening a few doors to see if some individuals that would fall into the cracks, if it could be hinged a bit." —Staff

"Door hinging" is a good metaphor to describe the role for a Transition Coordinator to expand a safety net that is currently failing to support individuals with a disability.

## Transition to adulthood

Individuals with FASD identified the main challenges of transitioning to adulthood as life after high school, moving out, and managing their finances. Being an adult means having a lot of responsibility, and some expressed dread at the consequence of forgetting to pay rent and becoming homeless, for example. They struggle with living in a new environment without reminders of rules and structure, that is often part of living with parents. They need help with motivation and feel that they are not necessarily consistent in terms of maturity, as they sometimes feel like a 16-year-old one day and 20-year-old another one. The impulsivity, failure to understand some links between cause and consequences and memory issues associated with FASD means that they might lack the cognitive resources to make good decisions on their own and compromise their safety.

“I and I think that for FASD, where money-making decisions come into hand, so it’s like when like you get your first credit card, and if you’re slower, you might not understand like the safeties and precautions you have to take. You might absolutely get scammed by shopping online. Oh, I won a vacation to Hollywood or something. So, I think that’s a big thing and stuff.” —Youth with FASD

Caregivers mentioned the dysmaturity (i.e., when one’s chronological age does not match their developmental age) as a major obstacle to transitioning into adulthood, since they feel their child is not always ready developmentally to live independently and hold employment. They feel that employers do not realize, for instance, that hiring someone with FASD is a long-term engagement requiring ongoing support over time. They also stated that they view differently the strengths of their child than themselves, as they do not assess or remember successes and challenges the same way individuals do. As one parent experienced: “Well, first of all, I just think they developmentally tend to be so much younger than their chronological age that I don’t really think they are to be independent, in many cases, at that age. But as a society, they are setting them up for failure if we give them too much independence too early.”

As for professionals, they believe that the biggest challenges associated with the transition to adulthood is turning 18. “From my experience, and my previous experiences also, when you are becoming an adult and passed 18 in Ontario, for services, clearly, the services, especially with people who have FASD, the services kind of stop.” Accessing services becomes difficult, as the supports that the child received all their life from the school or health systems are no longer available. Moreover, the biggest difficulty comes from the individuals not always understanding the implications of being an adult, which means having certain rights and more responsibilities as well. One worker provides a telling example of a youth with FASD failing to understand the consequences of stealing cigarettes after they become an adult.

“But I’m not sure that somebody who becomes, somebody that is 20 and is doing something that is considered illegal or reprehensible by law could grasp: ‘OK, this is not like before. If I would steal a pack of smokes, it would do this, and I would



be controlled. Now, if I steal a pack of smokes, when you are 20, then it's different.' And that's what I find the biggest challenge for them. It's actually to 'Wow! This is the world now, and I actually have power in the decision-making, but the responsibilities that come with the decision, it's...' And I could find that talking to the individual, and mostly one that was in situations that it was really clear that he knew, but it was... He knew of the consequences, he knew of the right thing to do, but it was not entirely clear how he could get out of that. The legal system, or the lack of housing system, or the lack of support systems. That's what I find is the biggest challenge: how to, 'OK, I could do this, and I could do this...'"—Staff

Another staff used the analogy of "hand-holding" to explain the process of accompaniment. This does not mean that the worker should do everything for the person with FASD, but that they struggle with things that other individuals might not, like filing out a form for instance.

"Because, again, so many of our clients, young adults, and the youth transitioning to adulthood, they do need, if you wanna use an analogy, 'hand-holding'. You know, they are so fearful, often they are too afraid to go and, for example, say: 'I need an application for ODSP.' That's huge for them. So that one-to-one time is crucial, I think." —Staff

There is a propensity for young adults with FASD to be caught in a vicious circle where they cannot secure employment or basic income and thus live in poverty, do not have adequate housing, and suffer from mental health and addiction issues because the uncertainty of the situation, causing low self-esteem.

"The specific challenges, again, are finding a place in the community where they feel they are contributing whether that is through volunteer work or meaningful employment. I think that is huge. And of course, if you can't, if you feel you are not contributing, and you are not working, and you can't have any sort of livable income, which ODSP and Ontario Works, you know, keeps people in poverty; then, of course, you have trouble finding safe housing, and nice housing, so you know you are living in the depths of despair and... A city-owned housing where there are lots of issues, and people with FASD are very easily influenced, and they are vulnerable, and so their housing needs should be really looked at in terms of safety and supports. There is not enough supported housing in our community at all. So those are big issues. Employment, volunteer work, housing. And be able to live with dignity with at least a basic income that meets your basic needs and not have the struggle, constantly in poverty, which then leads to an increase in anxiety and depression, and then mental health and addictions. Those are probably the main issues that I see quite consistently with our young people, and with young adults with FASD." —Staff

Being an adult implies the capacity to be organized in several aspects of one's life and be motivated to accomplish chores; this involves being able to remember appointments and showing up at the right place, at the right time. Or being able to use some means to be able to do so (i.e., phone reminders or visual cues). Because of their disability, many young adults with FASD are lacking opportunities because they do not have the proper support to seize them and to be successful in clearing the obstacles from the path toward the achievement of their goals.



## Conclusions

### Answers to the Research Questions

To go back to the research questions this pilot project sought to answer, a few answers can now be provided.

#### Distinct Needs of Individuals with FASD Transitioning to Adulthood

Individuals with FASD need accompaniment and regular check-ins, positive messaging, and ongoing support throughout their lifespan to help them live the best life they can. They need help with next steps after high school (which may include further education, employment, or life skills training), moving out of either their parents' place or foster care to some sort of interdependent living arrangement, managing their finances, and coping with rules and responsibilities related to becoming an adult. They do not always understand their rights and are vulnerable to abuse. Because of their disability, they, in majority, live in poverty and are at risk of homelessness, risk having significant mental health and addiction issues, as well as being socially isolated and feeling lonely. Those needs differ from early childhood ones, which are supported by the school and health care systems. As an adjunct support to the FASD Worker Program, this pilot project demonstrates the need for continued support after age 18 with an emphasis on developing an individualized plan that builds on strengths, compensates for challenges, and which truly is based on the individual's vision of their future. Transition Coordinators attempt to put into place a safety net along with mentoring individuals to adopt healthy coping mechanisms when clearing obstacles from their paths.

#### Independent Facilitation as an Evidence-Based Transition Model

On the basis of interviews conducted with young adults, caregivers, professionals, and staff involved with the pilot project, Independent Facilitation appears to be a positive model of intervention to support individuals with FASD. Support from a Transition Coordinator enabled participants to reduce social isolation and feelings of loneliness, build self-esteem, and work toward making friends, finding employment, and finding appropriate housing. It is limited, however, in the sense that these supports cannot be restricted to a short period of time in order for accomplishments to be sustained over time. Moreover, as many individuals with FASD are living in a state of poverty, or uncertainty, Independent Facilitation amplifies and does not address the barriers that are either systemic, clinical or financial in nature. This means that Transition Coordinators must have access to an extensive toolkit of skills, connections, and be resourceful. Independent Facilitation relies on the relationship developed with the individual as a basis for support, and thus is more suited to the task than many other transition models.

The flexibility of this approach (i.e., the accompaniment of self-determined goals; the brokering, accessing and tailoring of services in the development of informal support with respect to the individual's vision) is more likely to encounter success than rigid programs of assessment and intervention that prescribe what clinical recommendations individuals with FASD must follow. Independent Facilitation overcomes some of the limits of the

financial, housing, judicial or health/mental health systems. It is more efficient because it operates on the periphery of institutional systems, rather than being constrained by their internal logic, often at odds with the wellbeing of the person they are supposed to support or protect.

#### Successful Interventions to Reduce Social Isolation and Feelings of Loneliness

Interventions that were successful to reduce social isolation and feelings of loneliness were driven by the individual. Caregivers have confirmed time and again that their child does not follow through on programs or services they do not have an interest in. Many participants mentioned that they were able to make new connections because of the virtual support group for youth with FASD, launched in response to the related to the COVID-19 pandemic measures. This offshoot of the project was successful in the context of the pandemic, albeit not necessarily a community-based initiative, such as an interest group, community meetups, or other type of social club. This speaks to the fact that many individuals with FASD often make new friends easily because of disinhibition and impulsivity, but struggle to maintain these relationships over time because of dysmaturity and deficient adaptive skills. Having a semi-structured environment to support safe socializing between individuals with FASD of an appropriate age group appears to be a good solution to these issues.

#### Assessment of the Success of the Pilot Project

Overall, the project was successful in reducing social isolation and feelings of loneliness, despite the COVID-19 pandemic. Some goals were completed, new ones were created; some were stalled or stopped, and no circle of support meeting was realized. The Social Provision Scale survey results showed an increase in the number of social connections. Interviews confirmed that participants felt they had more people in their lives after the project than before. While self-determined goals were partially achieved because of constraints regarding access to physical spaces or placements being cancelled, the project was highly successful in attempting to prevent crises or supporting individuals in tackling challenges specifically related to transitioning into adulthood, such as managing addictions, mitigating homelessness, overcoming financial abuse and accessing health care, etc. This initiative definitely contributed to improving the mental health of the participants who followed through the project until its completion. The pilot project was exceptional in the sense that Transition Coordinators provided support creatively during the COVID-19 pandemic and project management went beyond their initial mandate in applying for external funding, thus providing electronic devices to enable individuals to remain connected during times of extreme social isolation.

## FORMAL CONNECTIONS ESTABLISHED DURING THE PROJECT

|                                |  |
|--------------------------------|--|
| <b>Community Organizations</b> | <ul style="list-style-type: none"> <li>✓ Ottawa Swordplay</li> <li>✓ Welding Shop</li> <li>✓ Sit with Me (Animal Shelter)</li> <li>✓ Ottawa Dog Rescue</li> <li>✓ Navan Animal Rescue Corporation</li> <li>✓ Wabano Centre for Aboriginal Health</li> <li>✓ Legal Aid Ontario</li> <li>✓ Housing Help</li> <li>✓ Action Housing</li> </ul> |
| <b>Colleges</b>                | <ul style="list-style-type: none"> <li>✓ Carleton University</li> <li>✓ Algonquin College</li> </ul>   |
| <b>Service Agencies</b>        | <ul style="list-style-type: none"> <li>✓ ABLE<sub>2</sub></li> <li>✓ Ottawa Withdrawal Management Services</li> <li>✓ LiveWorkPlay</li> <li>✓ John Howard Society (JHS)</li> <li>✓ Ottawa Victims Service (OVS)</li> <li>✓ Canadian Mental Health Association (CMHA)</li> <li>✓ Dual Diagnosis Service</li> </ul>                          |
| <b>Governmental Services</b>   | <ul style="list-style-type: none"> <li>✓ Ontario Disability Support Program (ODSP)</li> <li>✓ Indigenous Services Canada (ISC)</li> <li>✓ Service Ontario</li> </ul>   |



## Recommendations

### Moving Forward

The expert opinion provided by this report is that this transition project would benefit from being replicated for a longer period of time. This would enable the gathering of further evidence of the impact of Independent Facilitation as an intervention model for young adults with FASD, without the extraordinary circumstances and professional challenges that the COVID19 pandemic presented to the youth with FASD and Transition Coordinators. Offering Independent Facilitation to young adults with FASD for a longer period of time would allow for efficient initial contact, building of the relationship, and for the development of social and informal support networks that sustain planning. More space and time can be dedicated to individuals with FASD to process information adequately because of their need for constant reminders related to cognitive impairments. The informal connections and supports for planning and realizing goals sustained over time may in fact reduce the need to access formal subsidized services.

This report recommends that transition planning be accessible to individuals with FASD aging out of the FASD Worker Program, so that Transition Coordinators would support them from ages 19-39, in recognition of the fact that the transition to adulthood happens much later with this population.

### Guidelines

Because of its flexible approach, Independent Facilitation is a feasible intervention model to adequately support individuals with FASD that are transitioning to adulthood. Though the approach does not necessarily rely on formal services, individuals with FASD often do require formal support that exists, but for which they do not qualify, and so are not tailored to their needs. The systemic challenges that these individuals are facing with regard to insufficient basic income, lack of accessible and safe housing or criminalization of mental health and addiction issues are constant barriers with which they have to deal.

Furthermore, since FASD is a lifelong disability, there is a need for ongoing supports throughout the lifespan of the individual. Ideal support services must be offered for a long period of time, with high staff retention rates and a smooth transfer of clinical case notes. Workers must be trained on FASD and have an appropriate attitude/outlook. There must also be a sensible match between the worker and client personalities. Flexibility is key: initial contact should offer multiple choices to establish a relationship and trust, such as through phone contact, one-to-one contact, or group contact. It would also be appropriate to discuss and establish parameters of involvement from caregivers or professionals with participants in the process of planning goals, as they often are ensuring continuity between steps and services.

Clarification of the role of Transition Coordinators is necessary to avoid the risk of duplicating limited existing services (e.g., case management, counselling, social work, employment support, etc.) and programs (e.g., ABLE2's Matching Program or Lifetime

Networks, MCCSS employment support services, etc.), given that different stakeholders may have different expectations toward Transition Coordinators and their expertise. Moreover, there must be significantly more organizational and institutional supports provided, as the emotional work of supporting an individual with FASD takes a toll and often lead to both caregiver and staff burnouts if left ignored or unattended. A more formalized process to gather consent and relevant background information should be considered for the safety of the individual and the worker prior to engagement.

At any time, workers should have access to direct referral pathways and clinical consultation with a wide range of experts to provide the most appropriate support they can offer. Since individuals with FASD often require prompt support beyond regular work hours to prevent crisis, a support service should be introduced to address emergencies as they arise. Workers have to take into consideration multiple supports for basic needs such as health and safety when planning for self-determined goals. Otherwise, there is a risk that medical issues could be treated as mental health issues, for example. Independent facilitation as an intervention for young adult transitioning to adulthood is promising, but there is no magic bullet to solving every problem.

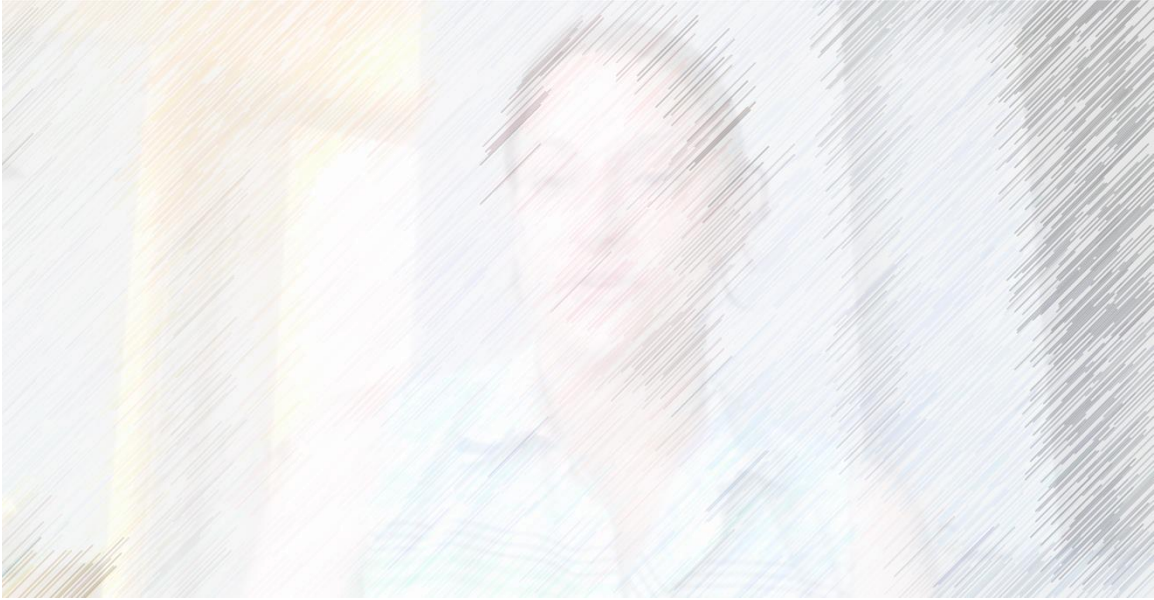
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