



Supporting Employment in Individuals with FASD

A Guide for Employment Professionals

Final Report Prepared by the Canada FASD Research Network

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FOREWORD

In this report, we present findings from a project focused on successful employment for individuals with Fetal Alcohol Spectrum Disorder (FASD). A guide was developed for use by employment professionals to support individuals with FASD in preparing for, obtaining, and maintaining employment. Our report begins with an introduction to FASD and the complex employment-related challenges this population faces. Next, we provide a description of the two phases of this project: 1) collecting employment stories and 2) developing the employment guide. We share information about our collaborators, including the CanFASD Family Advisory Committee, and numerous employment organizations supporting individuals with FASD. We then describe outcomes from the research conducted, present take home messages, and address next steps and recommendations for future projects. It is our hope that the materials provided here will guide employment professionals through the process of supporting this complex population towards employment success.

EXECUTIVE SUMMARY

When appropriately supported, individuals with Fetal Alcohol Spectrum Disorder (FASD) have the potential to experience employment success, which can contribute to increased quality of life. However, many individuals with FASD face challenges in obtaining and maintaining employment due to the underlying cognitive, physical, emotional, and behavioural difficulties that characterize this population. These difficulties are compounded by social stigma and a lack of shared understanding in the community. Employment programs exist to support individuals with FASD, and professionals in this field have called for guidance regarding best practices in this area. This project was developed with support from the community to first better understand employment success in adults with FASD, and to then use this understanding to create an employment guide for assisting employment professionals working with adults with FASD.

PHASE 1: INFORMATION GATHERING AND DEFINING SUCCESS

There is currently very little empirical evidence informing employment best practices for individuals with FASD. Consequently, the first step in this project required reaching out to experts in the community to begin defining employment success for this group. The experts were employed adults with FASD, as well as their caregivers and support professionals, who were all recruited to complete a survey about the employment journeys of adults with FASD. The design of this survey was based on previous research conducted in the area of employment and FASD, which has identified common challenges that individuals with FASD face, but has not provided much information about how to foster employment success. Input from families of individuals with FASD was also incorporated into the survey design. The aim of this survey was to learn *what can employment success look like for adults with FASD?* In addition to the survey, participants also had the option to complete a video interview about their employment story.

Overall, 32 surveys were completed, and three video interviews were conducted. Frequency and descriptive data was obtained from closed ended questions. Key findings from this data included:

- Participants reported being employed in a wide range of settings, including the service industry, government, and home businesses.
- The most frequently reported length of employment was between one to five years (34%), and participants reported mostly working either 1-2 days

- a week (38%) or full time (38%).
- 63% of participants reported that it was difficult to find employment, and 72% reported they had lost a job in the past.
- Participants also endorsed factors that helped them at work such as routine (72%), someone to explain things to them (72%), lists (53%), someone to help with paperwork and filling out forms (47 %), and reminders or alarms (38%).
- Almost all (88%) participants reported that they had someone who helped them with work, including family (41%), friends (28%), support worker (47%), or a role model (56%).
- The majority (69%) of participants chose not to disclose their FASD diagnosis at work.
- The majority (91%) of participants were paid for their work, and many (63%) reported receiving some benefits, such as vacation time.

Open-ended responses were also analyzed, and two factors that emerged as being essential to employment success were [Job Fit](#) and [Relationships](#).

[Job Fit](#) refers to how well an employee is suited for their position. When the employee and workplace are a match in regard to factors such as the employee's interests, skills, and goals, the job is a good fit. Participants reported that when they experienced job fit, they experienced success through a sense of independence, increased confidence and pride, enjoyment of work, and gaining new skills. When a job is a good fit for an individual with FASD, the individual does not feel stigmatized at work. The workplace offers supports and accommodations for physical and cognitive challenges, mental health or stress concerns, and scheduling needs. Some strategies that were reported to be helpful with job fit included individualized accommodations such as a special chair, reminders, receiving special training, and a well-developed routine and schedule.

[Relationships](#) are the second factor that emerged as contributing to employment success. When employees with FASD had personal supports and positive relationships with their supervisors and coworkers, they experienced employment success. Individuals with FASD identified relationships with family members, a support worker, and people at work as contributing to their employment success. Ways that positive relationships increase employment success included providing positive feedback, transportation to work, help creating a work schedule, and support obtaining employment. When individuals with FASD had positive relationships at work, they experienced more open communication, more mentorship, and an increased understanding of FASD in the workplace.

PHASE 2: DEVELOPMENT OF AN EMPLOYMENT GUIDE FOR FASD

Following the employment success survey, we developed a guide that provides a standardized process for assisting employment professionals to help clients with FASD obtain and maintain successful employment. The purpose of the guide is to help professionals evaluate their work and progress in supporting adults with FASD towards increased employment success. This guide is designed to mitigate challenges through effective strategy use, as well as placing a focus on job fit and relationship building. By doing so, individuals with FASD are supported to become and stay successfully employed in a way that is individually tailored to their strengths and needs.

The development of this guide is the result of collaboration with community employment agencies, a review of employment literature, and the results of the employment success survey.

Well-being is placed at the forefront of the guide, which reflects foundational factors in a client's life that can impact their employment success, including stability and basic needs, family and friend support, mental health, legal issues, and children/dependents. It is recommended that the well-being section of the guide be completed periodically with clients.

The **work factors** section is divided into three categories: **prepare**, **obtain**, and **maintain**. These were designed to help employment professionals support the trajectory of clients through their employment experiences. Employment professionals must first help clients *prepare* for employment, which includes understanding and developing employability skills, and understanding what jobs would fit for the client's unique interests, training, and abilities. Next, clients may move into the *obtain* phase, where they are looking to gain employment. Areas in this category include job searching, and assessing potential jobs based on the client's employability skills and job fit criteria. Once they are employed, clients move into the *maintain* phase. The employment professional is encouraged to periodically assess that the job remains a good fit for the client, continues to match their employability skills, and encourages on-going conversations and relationship building between the employee, employment professional, and employer.

Validity, utility, and feasibility of the guide was explored through feedback from employment agencies. This feedback was incorporated, and the guide was converted into as a form fillable pdf document (see attached). The guide will be available on the CanFASD website.

BACKGROUND

Fetal Alcohol Spectrum Disorder (FASD)

FASD is a diagnostic term that describes the range of disabilities resulting from prenatal exposure to alcohol. FASD is the leading known cause of preventable developmental disability among Canadians (Koren, Nulman, Chudley, Looock, 2003). Current prevalence estimates of FASD are approximately 1.1%-5.0% of children (May et al., 2018; Popova, Lange, Chudley, Reynolds, & Rehm, 2018), and associated lifetime costs have been estimated to be more than one million Canadian dollars for some individuals (Popova, Stade, Bekmuradov, Lange, & Rehm, 2011). The disability can be mild to severe, and include physical and mental difficulties that involve cognition, behaviour, and emotion.

When supported, people with FASD can lead fulfilling lives and become contributing members of society; however, without support, adverse outcomes such as addiction, incarceration, and unemployment have all been well documented in the literature (Streissguth et al., 2004). Most individuals with FASD have no physical indication of disability, and consequently FASD is considered to be largely invisible; thus, it can compromise the chances for success and adversely affect quality of life.

Employment and FASD

Competitive and fulfilling employment can help contribute to the development of positive identity, self-esteem, and self-worth for all people. It provides opportunities to connect with others, develop oneself, feel useful, and offer a socially valued role. Employment can also be a protective factor against some of the adverse outcomes associated with FASD, and can reduce poverty and dependency. However, many researchers recognize that individuals with FASD have employment-related challenges (Baldwin, 2007; Streissguth, Barr, Kogan, & Bookstein, 1996).

Unfortunately, cognitive and behavioural difficulties, as well as some preconceived negative beliefs (stigma) about FASD make it challenging to join and stay in the workforce (Salmon & Buetow, 2012). Individuals with FASD have unique and diverse cognitive difficulties associated with their disability which may manifest as an inability to pay attention and/or sit still for long periods of time, impulsive behaviour, trouble remembering instructions, tiring easily from having to think and

concentrate harder than others, and being slow to perform duties. Additionally, the lack of understanding among employers and coworkers regarding the cognitive and behavioural challenges associated with FASD can place increased pressure on the individual and may create expectations that are unattainable and/or unfeasible. Having criminal records, minimal support networks, addictions issues, and a lack of understanding of employment expectations are additional barriers that adults with FASD may face on their employment journey.

Although adults with FASD experience vocational challenges both directly (i.e., inherent with their diagnosis) and indirectly (i.e., via their employer), it is important to recognize the many strengths, skills, and abilities that adults can contribute to society. For example, some common traits for individuals with FASD include curiosity, creativity, gregariousness, tenacity, friendliness, helpfulness, and generosity. Many adults with FASD also are very artistic and perform well in environments where routines and structure are well established (Community Living British Columbia, 2011).

Employers who understand these challenges and adapt their processes, interactions, and expectations so they are manageable to clients with FASD create a mutually beneficial situation. These shifts can empower clients to overcome difficulties and retain paid employment that makes them feel valued and increases self-esteem (Salmon & Buetow, 2012).

Employment Models

As communities move towards more inclusivity, supported employment models are beginning to replace sheltered employment models. A sheltered employment model is one where clients work in segregated work environments and are not paid meaningful wages. Alternatively, a supported employment model focuses on creating a good fit between the employee's abilities and work environment, and providing individualized guidance for individuals with disabilities. This model works to integrate individuals with disabilities into the workplace. In a supported employment model, organizations and agencies provide support to clients that can maximize their chances for success (Hale, Stainton, & Tomlinson, 2011).

Knowledge Foundation

CanFASD researchers conducted a literature and program review of programs in Alberta and across Canada that specifically serve individuals with FASD in employment. Nine employment programs reported on their processes, capacity, approach, success indicators, strategies, challenges, and funding models. The researchers identified several factors that promoted success, including relationship

building between support staff and clients, and between the employer and support staff. A strength-based approach was identified as most effective when working with clients with FASD, although it was also described as resource-intensive in terms of staff time and flexibility. Education, awareness, and support were also identified as significant contributors to the overall success of the employment opportunity for adults with FASD (Green, 2016). The researchers urged employment agencies to educate prospective employers about FASD and emphasized the importance of working collaboratively to support these clients.

Concluding Thoughts

Adults with FASD are unique and diverse. Many adults with FASD are not able to pursue competitive employment and may qualify for assured income supports. Others may be able to experience success in volunteer positions that provide meaningful community engagement. For many adults with FASD, stabilizing housing, addressing mental health needs, or managing addiction and recovery takes priority over employment. Still, others are gainfully and competitively employed. We asked some of these adults for their stories so we could learn from their successes and their diversity, and work towards best practices for supporting adults with FASD in preparing for, obtaining, and maintaining employment.

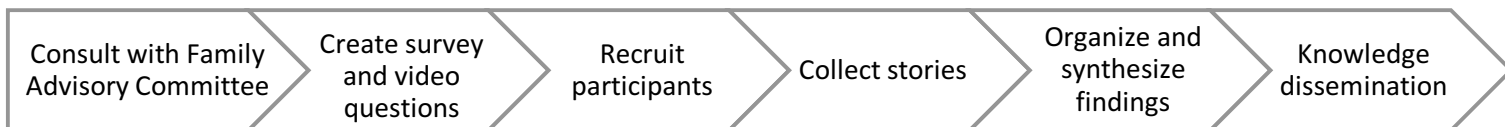
PHASE ONE

INFORMATION GATHERING AND DEFINING SUCCESS

The first phase of this project was aimed to explore what constitutes success in employment for people with FASD. Specifically, the goals for this phase were to identify:

1. What kinds of **positive outcomes** are being achieved?
2. Under what **conditions** are people with FASD successful in their employment?
3. What are some of the different **trajectories** of success for individuals with FASD?

The following process was followed in the development of the survey and sharing of results.



FAMILY ADVISORY COMMITTEE (FAC) CONSULTATION

The FAC is a group of committed parents and caregivers of individuals with FASD who are interested in how FASD research can improve the quality of life for individuals with FASD and their caregivers. The mission of the FAC is to advise on CanFASD research priorities for families impacted by FASD, and to assist in translating results of research to ensure they are accessible to families.

SURVEY DEVELOPMENT

The survey was designed based on:

1. The existing CanFASD literature and program review.
2. Valuable input from FAC regarding survey content, item wording, and the optimal mode of data collection.
3. Supported employment literature and best practices.

Based on the three goals of the survey, questions focused on both challenges and successes that individuals with FASD may experience in their employment journey (see Appendix A for full survey). Both open-ended and closed questions were used to obtain a variety of information targeting the three goals of the study. Examples of questions that addressed *positive outcomes* included: What have you learned at your job? What do you like about your job? Has your job changed since you started? Examples of questions that addressed *conditions for success* included: How do you know you are doing a good job? Did you disclose your FASD diagnosis? What strategies help you with work? Examples of questions that addressed *different trajectories* included: Where do you work and what do you do? How many days and hours do you work? Have you ever lost a job?

RECRUITMENT

We recruited three groups of individuals in order to gather multiple perspectives on employment of adults with FASD. The three groups were:

1. Adults with FASD who are employed.
2. Support professionals directly connected to an adult with FASD who is employed.
3. Family members of an adult with FASD who is employed.

Our method of recruitment involved contacting existing and well-established networks. In particular, the following six networks assisted with recruitment:

1. CanFASD blog – canfasd.wordpress.com – and other CanFASD social media
2. CanFASD Family Advisory Committee
3. FASD-ELMO Network
4. Attendees at the 2017 International Conference on FASD (April)
5. Attendees at the 2017 National FASD Conference (October)
6. Alberta FASD Service Networks

We also included an item in the survey asking if participants with FASD would like to film a video about their employment journey, and those who were interested were interviewed on camera.

DATA COLLECTION

Survey responses were collected between March 2017 and August 2017 in one of three ways:

1. Online by the participant.
2. On the phone with a researcher.

3. In person at the International Conference on FASD (April 2017)

The online survey was created and a link to the survey was distributed in recruitment. A paper version of the survey was also available for participants who preferred to complete it in person. See full survey in Appendix A.

PARTICIPANTS

Out of 49 surveys started, 32 were completed. We received 20 surveys from adults with FASD, and 12 from caregivers or support persons who responded about their child/dependent or client's work experience.

Survey demographics:

- Gender: 20 women; 11 men; 1 prefer not to say
- Nationality: 26 from Canada, 5 from USA, and 1 from South Africa
- Average age: 31.15 years (range 14 to 64 years)

SURVEY DATA RESULTS

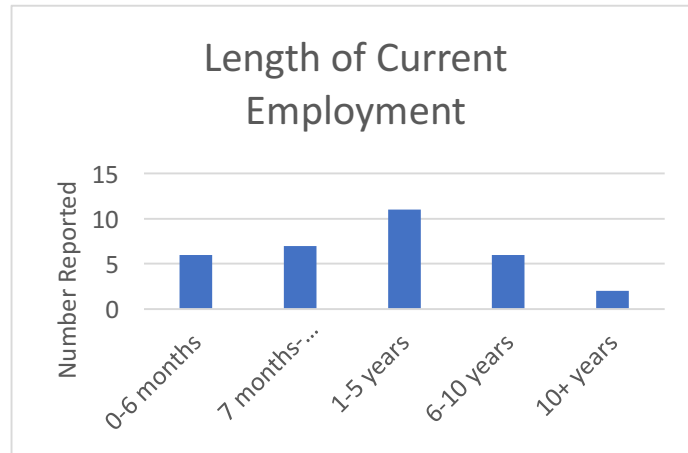
Descriptive Survey Results

Closed-ended questions were analyzed for frequency and descriptive information. Data was collected on the types of jobs, length of employment, work schedule, challenges obtaining and maintaining employment, supports and strategies, disclosure of FASD diagnosis at work, and pay and benefits.

Places of Employment. Participants reported being employed in a wide variety of settings that require a broad range of skills, and foster development of various abilities and areas of growth. The service industry was the most commonly reported workplace (e.g., restaurants and cafes) for individuals with FASD, but overall, the workplaces participants reported were diverse.

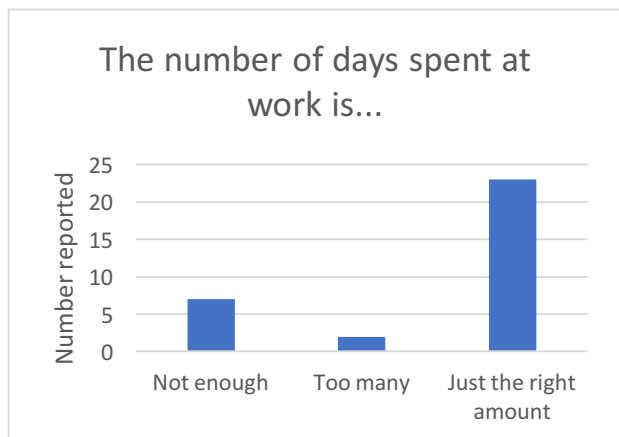
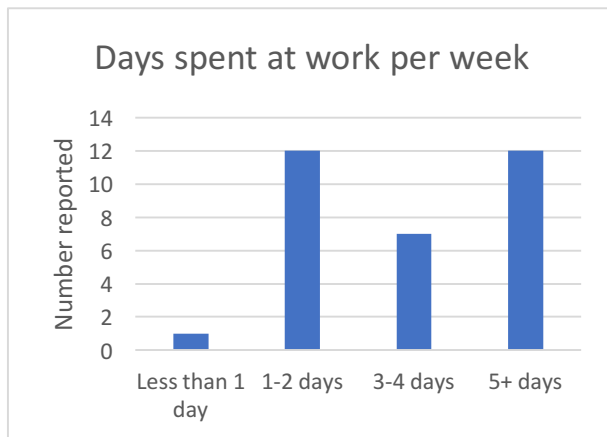
- Support Services
- Restaurants and Cafes
- Transit
- City/Government
- Delivery
- News Company
- Home Business
- Repair Shop
- Events Planner
- Retail
- Manufacturing
- Recreation
- Construction
- Hotel

Length of Employment. Participants most frequently reported working at their place of employment between one to five years.



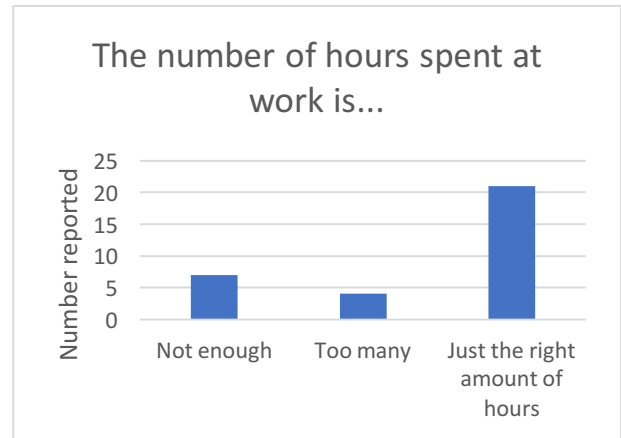
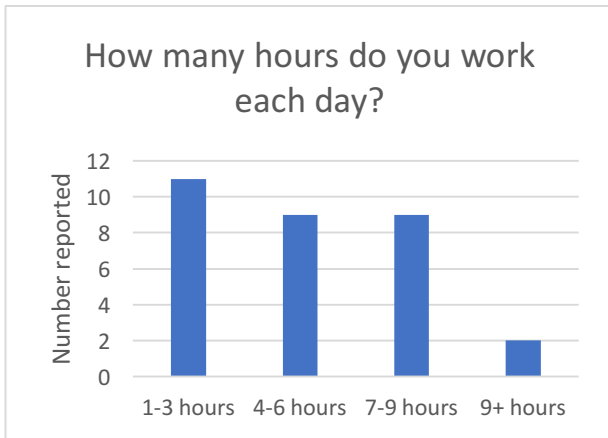
Total=32

Employment Schedule. An equal number of participants reported working either 1-2 days a week or full time, and the majority of participants reported that the number of days they worked was just the right amount.



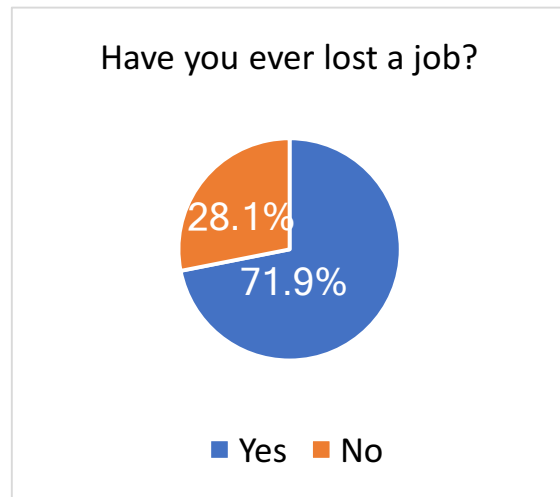
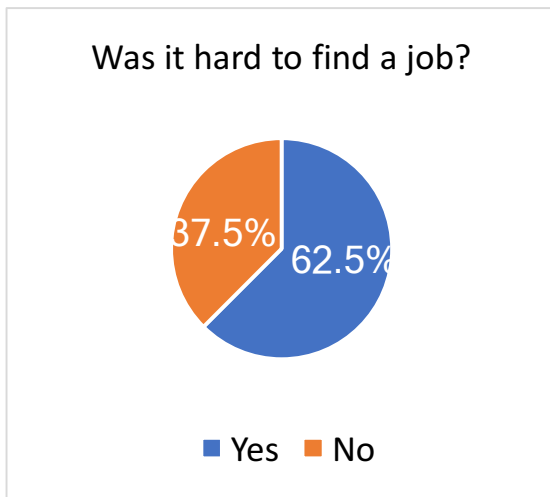
Total=32

The most frequently reported number of working hours a day was 1-3 hours, and the majority of participants reported that the number of days they worked was just the right amount.

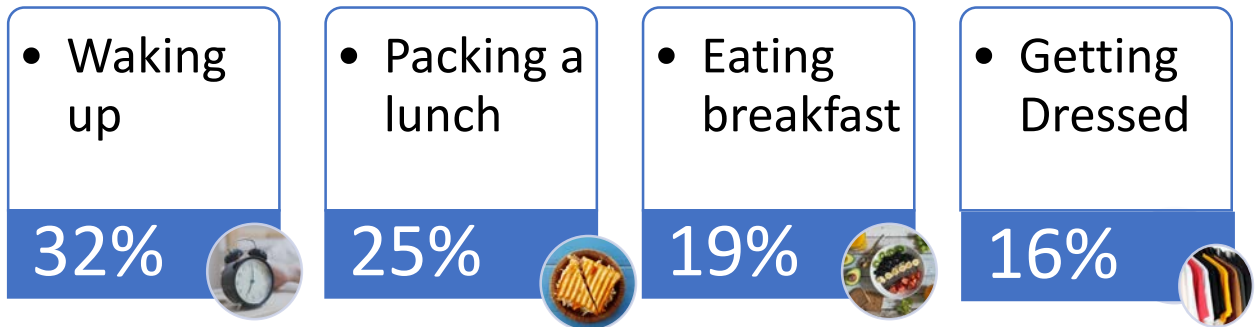


Total=32

Obtaining and Maintaining Employment. The majority of participants reported that it was difficult to find employment, and most also reported they had lost a job.



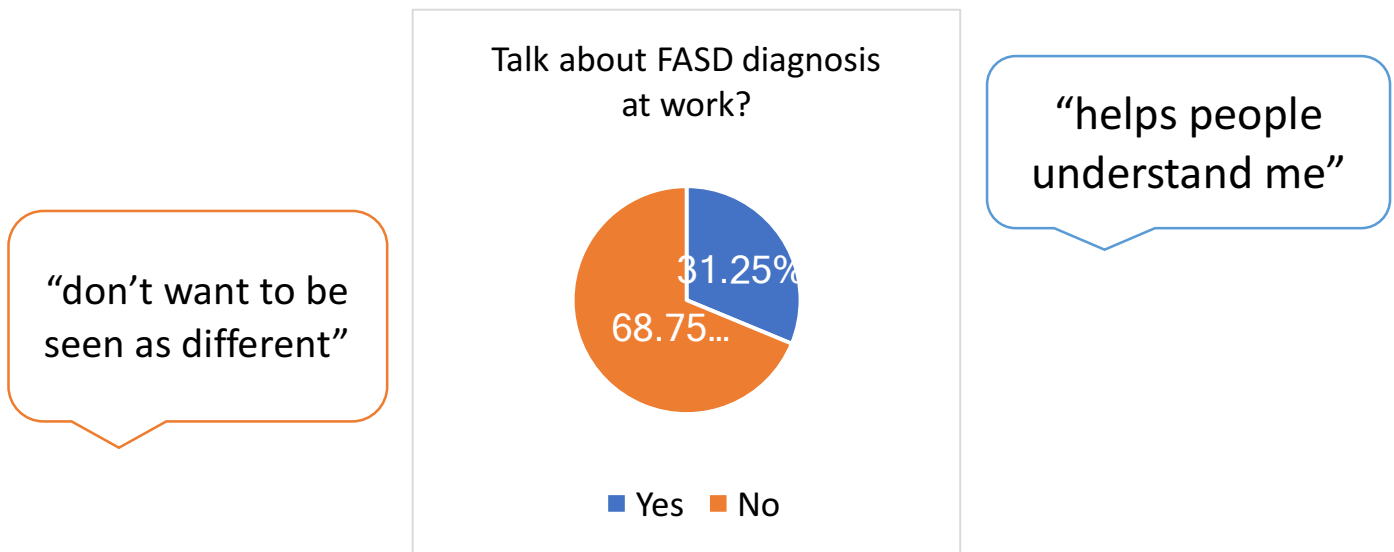
Help Getting Ready for Work. When asked about what individuals with FASD needed help with when getting ready for work, the most common response was help waking up. Next, individuals reported needing help packing a lunch, eating breakfast, and getting dressed. Other activities that required help included taking medication, transportation, hygiene, and weather considerations.



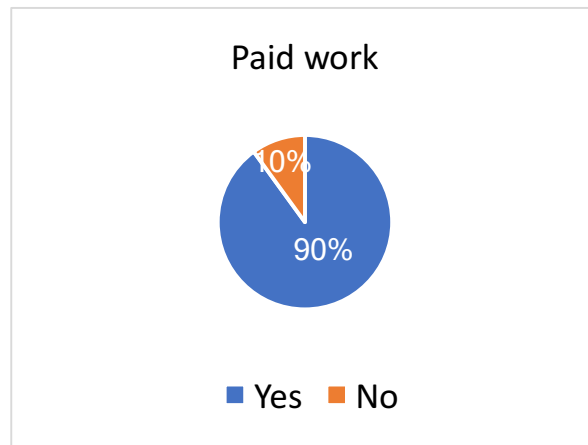
Personal Supports and Strategies. Almost all participants reported that they had someone who helped them with work, including a role model (56%), family (41%), a support worker (47%), or friends (28%). Other people who reportedly helped at work were managers and supervisors.

Participants also endorsed factors that helped them at work such as routine (72%), someone to explain things to them (72%), lists (53%), someone to help with paperwork and filling out forms (47%), or reminders or alarms (38%).

Disclosure of Diagnosis. The majority of participants chose not to disclose their FASD diagnosis at work. However, those who did reported that disclosing their diagnosis helped people better understand them.



Pay and Benefits. The majority of people were paid for their work, and many (63%) reported receiving some benefits, such as vacation time, dental coverage, health coverage or “other,” which included staff discounts, or a pension.



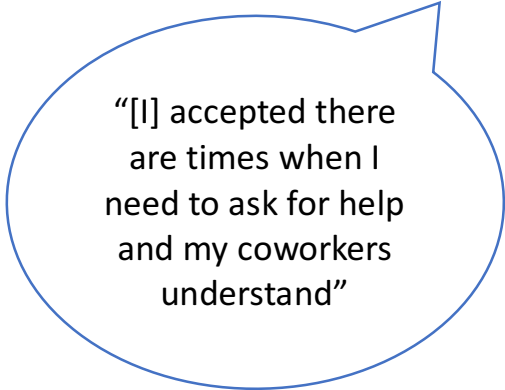
Content Analysis Results

The open-ended survey responses were analyzed, and participants described two broad factors that were most influential in shaping their employment experience: **Job Fit** and **Relationships**. Two researchers worked together to ensure agreement among the interpretations of the responses.

Job Fit. This factor refers to how well an employee is suited for their position. When the employee and workplace are a match in regard to factors such as the employee’s interests, skills, and goals, the job is a good fit. Participants reported that when they experience job fit, they experience success through a sense of independence, increased confidence and pride, enjoyment of work, and gaining new skills. When a job is a good fit for an individual with FASD, the individual does not feel stigmatized at work. The workplace offers supports and accommodations for physical and cognitive challenges, mental health or stress concerns, and scheduling needs. Some strategies that were reported to be helpful with job fit included individualized accommodations such as a special chair, reminders, receiving special training, and a well-developed routine and schedule.

“I learned to communicate better with people and to be patient. I have also learned that things change and I have to be flexible”

Relationships. Relationships are the second factor that emerged as contributing to employment success. When employees with FASD have personal supports and positive relationships with their supervisors and coworkers, they experience employment success. Individuals with FASD identified relationships with family members, a support worker, and people at work as contributing to their employment success. Ways that positive relationships increase employment success included providing positive feedback, transportation to work, help creating a work schedule, and support obtaining employment. When individuals with FASD have positive relationships at work, they experience more open communication, more mentorship, and there is increased FASD understanding in the workplace.




“[I] accepted there are times when I need to ask for help and my coworkers understand”

STORIES OF EMPLOYMENT



An additional component of this project was interviewing employed adults with FASD about their jobs. Video interviews were conducted to provide an opportunity for these adults to share what their job means to them and what they want others to know about people with FASD and work. This medium has allowed for an engaging way to share positive information about employment in individuals with FASD, and for us to add success stories to the largely problems-focused FASD literature. Participants shared their stories on camera and consented to their videos being used in knowledge sharing activities. An excerpt can be accessed on the CanFASD blog at <https://canfasdblog.wordpress.com/>

We spoke to two men, a bus driver and a restaurant baker, and one woman, a helper at a gymnastics centre. They were from Edmonton, Red Deer, and Cold Lake, Alberta. Their stories give us real examples of success and provide inspiration to continue supporting individuals with FASD towards their own versions of employment success. Their unique stories demonstrate three different trajectories of successful employment for individuals with FASD.






Video Participant 1 proudly shared that he has worked as a **baker** in the same restaurant for 15 years. He said he loves that everybody helps one another as a work community. He explained that routine keeps him from getting lost, though it takes him months to find the right routine and figure out what works and what doesn't work to get his life running smoothly. His message for others with FASD is to never give up, no matter how frustrating or how hard it is. He believes the effort will always be worth it in the end. He shared that his biggest struggles as a baker are also his greatest accomplishments. He wants employers to know that people with FASD can perfect something one day and the next day they may have no idea how to do it. His message to employers is to hire people with disabilities, stating that "you won't regret it."



Video Participant 2 shared that he worked in several different fields and countries before becoming a **bus driver**. He said that he likes the variety in his job and he feels supported by his employer who knows about his disability. He also appreciates having a consistent paycheck and having a pension. He believes that staying positive and helping other people helps him to do his job well and he appreciates his mentor, supportive parents, and faith for helping him along the way. He stated that he wants employers to see the potential for people with disabilities to succeed. He learned to do things "my way" and find a way to work around his struggles, like taking extra time to complete training.





Video Participant 3 shared that she has worked at a **gymnastics centre** for 7 months. She said she likes working with kids and is happy she hasn't been fired. She finds that getting enough sleep and not being exhausted helps her to do her job well. She also explained that she needs a ride to work because she can't drive. Her message to others with FASD is that it might be hard to get a job, but there is always going to be a job that is pretty good for you.



Take Home Message. These stories exemplify the importance of job fit and supportive relationships in fostering employment success for individuals with FASD. Each of our video participants wanted others with FASD to know that there will be challenges in their employment journeys. However, they also spoke about moving forward through persistence, hard work, working collaboratively, and relying on supports to achieve their goals and ensure they have what they need to feel successful. Having these stories on video for sharing with other individuals with FASD, employment professionals serving individuals with FASD, family members, employers, and the community is a valuable part of this project.

PHASE ONE KNOWLEDGE DISSEMINATION

Makela, M., Pei, J., Parisian, N., Zink, H., Flannigan, K., & McFarlane, A. (2017, June). *Supporting Employment in Adults with FASD: Success, Hope, and Possibility*. Oral presentation at the 22nd Annual CASE Conference. Niagara Fall, ON.

The Canadian Association for Supported Employment (CASE) is a national association of community-based service providers and stakeholders working towards the employment inclusion of people with disabilities. This association strives to promote full citizenship and personal capacity for persons with disabilities through the facilitation of increased labour market participation and outcomes.

In our presentation at this conference, we discussed the complexities of employment for individuals with FASD and shared the preliminary results from our survey. Employment professionals from the Lakeland Centre for FASD presented on their experiences supporting adults with FASD and provided case examples of successes and challenges. We were able to connect with other employment programs and explore employment tools that have been developed for other disability populations.

Kapasi, A., Makela, M., Flannigan, K., & Pei, J. (2018, April). *Supporting Employment Success in Adults with FASD*. Oral presentation at the 8th International Research Conference on Adolescents and Adults with FASD. Vancouver, BC.

The International Research Conference on Adolescents and Adults with FASD is a multi-disciplinary conference that aims to identify, explore, and examine existing, new, and emerging research and the implications for those with FASD, families and caregivers, systems and services.

In the presentation given at this conference, we discussed the complexities of employment for individuals with FASD and described the work that led to this study. We shared the results from our surveys, presented a video clip, and answered questions from caregivers and service providers.

PHASE TWO

GUIDE DEVELOPMENT

In the second phase of this project, we worked collaboratively with community members to develop a guide that provides a standardized process for assisting employment professionals through their work with adults with FASD as they help them prepare for, obtain, and maintain employment.

The purpose of the guide is to help professionals formatively evaluate their work and progress in a way that is individualized to their client's strengths and needs. The guide is designed to support the evolving process of helping adults with FASD become and stay successfully employed through a focus on relationship building, job fit, and effective strategy use.

Community collaboration was an integral part of the development of this guide. We sought feedback from employment professionals working with individuals with FASD throughout its development. See attached for the full guide.

The following process was followed as we collaborated with community organizations to develop *A Guide for Employment Professionals: Supporting Employment in Adults with Fetal Alcohol Spectrum Disorder*.



LITERATURE REVIEW

A literature review was conducted to obtain current research evidence on employment and FASD, and to situate the current work within existing shared understandings around terminology and supported employment approaches. Since there is minimal literature on FASD-specific employment best practices, we explored employment literature in other disability populations and researched

employment tools that have been developed for disability and non-disability populations. Four broad topics were examined: employment definitions, factors that support job satisfaction and job fit, barriers to obtaining employment, and employer characteristics that promote success.

Employment Definitions. There is variability in how employment is defined in the literature. In order to ensure that our language is clear and consistent throughout this report and accompanying guide, we provide the following definitions, based mainly on Canadian Association for Supported Employment terms.

Competitive Employment: Full-time or part-time work consistent with the individual's choices. Wages (at or above minimum wage) and benefits are commensurate with those of coworkers in the same setting.

Supported Employment: Job seeker receives individualized help from support person to achieve successful employment. Job seeker, support person, and employer form a partnership to match the skills of the job seeker to the needs of the employer and to assist in the job seeker's career enhancement and long-term satisfaction for job seeker and employer.

Sheltered Employment: A setting (e.g., program, workshop) in which people with disabilities receive services and training to develop work-related skills and behaviours.

Self-Directed Employment: Income generating work where people with disabilities, to a significant degree, have a prime decision-making role in the kind of work that is done, how time is allocated, what kinds of investment in time and money should be made, and how to allocate revenue generated.

Supports. Researchers exploring job satisfaction have reported higher levels among people with intellectual disabilities working in an integrated employment setting than those working in a sheltered employment setting (Akkerman, Janssen, Kef, & Meininger, 2016; Test, Carver, Ewers, Haddad, & Person, 2000). The authors recommended that an integrative approach, which considers personal, situational, and social-cognitive characteristics is necessary to improve job satisfaction. There must be a **fit between the individual's needs and the work environment**. Some factors to consider with regards to enhancing job satisfaction include the employee's ability, cognitive characteristics such as motivation, and characteristics of the physical work environment, including the number of people in the workplace. Characteristics of the work itself to be considered are the tasks involved, job stressors, and psychological demands. Feelings of belonging, recognition, appreciation, lack of stigma, and support from coworkers and

supervisors positively relate to job satisfaction (Akkerman et al., 2016). Integrated employment has been associated with many benefits in comparison to sheltered employment, including better financial outcomes, opportunities for personal growth, incorporating the preferences of those with disabilities and their families, and greater social integration (Migliore, Mank, Grossi, & Rogen, 2007). Specifically, for individuals with intellectual disabilities, associations have been found between job satisfaction and job retention (Chiocchio & Frigon, 2006).

Barriers. Researchers studying youth with developmental disabilities in a supported employment program have identified several barriers to obtaining employment, including a lack of previous work experience, trouble with transportation, disengagement from the employment program, cognitive and behavioural problems, and a lack of social skills (Noel, Oulvey, Drake, & Bond, 2017). There were also familial barriers, such as families not prioritizing employment, holding low expectations for the youth's ability to hold a competitive job, preferring sheltered employment because it was the traditional course, and expressing concerns for the youth's safety (Noel et al., 2017).

Among adults with intellectual disabilities, researchers have found that employment in a competitive setting was more likely for those with a younger age, early work experience, higher adaptive behaviour, and the absence of emotional and behavioural problems (Siperstein, Heyman, & Stokes, 2014). This finding is particularly concerning for individuals with FASD, who often exhibit social, emotional, and behavioural difficulties, and may have cognitive impairment and struggle with adaptive functioning. Early work experience and family support both appear to be important factors for obtaining employment.

Employer Characteristics. Researchers have recently suggested that, among people with disabilities, organizational culture and practices contribute to the difficulties in obtaining employment (Erikson, von Schrader, Bruyere, & VanLooy, 2014). Some major factors that influence the hiring of people with disabilities are the inclusion willingness of managers, the organizational climate, and commitment to disability issues (Disability Case Study Research Consortium, 2008). Additionally, through focus groups with employees, employers, and placement service providers, researchers have identified three categories of key practices for the successful employment of people with disabilities: [work cultural issues](#), [job match](#), and [employer experience and support](#) (Gilbride, Stensrud, Vandergoot, & Gold, 2003).

[Work cultural issues](#) included equal treatment, a welcoming environment, focus on performance, and employer comfort in providing accommodations. [Job match](#) included obtaining input from the person with disability on their ability to perform

duties, focus on essential functions, and matching the worker with the job requirements. Lastly, **employer experience and support** included the employer's ability to supervise a diverse workforce, and the employer's tendency to view the rehabilitation program or agency as a partner and an ongoing employment support resource.

In another study, researchers described three practices that led to the implementation of disability-related policies, including: 1) having a centralized accommodation fund, 2) a formalized decision-making process for case-by-case provision of accommodations, and 3) establishing a disability-focused network (employee resource or affinity group) (Erikson et al., 2014). Erikson and colleagues (2014) also noted that professionals in the rehabilitation services should focus some of their resources on outreach and education efforts for human resources (HR) professionals. Building relationships between HR professionals and community agencies will build awareness of community employment resources for people with disabilities and promote proactive follow-up for the agencies.

In a scoping review, Karpur and colleagues found a lack of literature on employer practices for people with disabilities on topics of discipline, dispute resolution, termination, and retention and advancement (Karpur, Vanlooy, & Bruyere, 2014), highlighting areas where employers may need more guidance from service providers.

Employment Toolkits

In our literature review, we found no existing employment guides or tools specifically designed for supporting individuals with FASD. However, we reviewed various employment toolkits and best practice guides to inform the format and content of our guide. Some of these included the *Best Practices for Serving Individuals with Complex Needs: Guide and Evaluation Toolkit* (Pei, Poth, Tremblay, El Hassar, & Ricioppo, 2018), *Conference Board of Canada Employers' Toolkit: Making Ontario Workplaces Accessible to People with Disabilities* (Cameron, Vacha, & Niro, 2015), and the *Employability Skills Assessment Tool* (Futureworx, 2018).

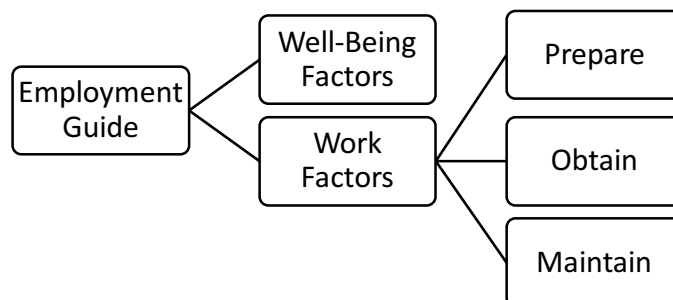
GUIDE DEVELOPMENT

The guide is a collection of form fillable checklists and reflective prompts that assist employment professionals in understanding their client's overall well-being and employment-related needs. It is meant to be completed on an individual basis, and can be done collaboratively with the client as they progress through their

employment path. The following section describes the collaborative process we undertook to develop the guide. The guide is in an attached document.

First Draft Process (September to December 2017)

1. We clarified the underlying principle of the guide in order to conceptualize the design. Our work was grounded in the belief that the guide needed to be growth-focused, strength-focused, reflective, empowering, and individualized to the unique needs of the FASD population. We also considered how we could design the guide to facilitate reflective, solution-focused, and action-based practice and track progress towards goals.
2. We created a Program Logic Model to inform the first draft of the guide.
3. We developed a conceptual framework for how the guide should be organized, structured, and prioritized while considering what would be sensible and valid for employment professionals working with individuals with FASD. Two factors were created within the guide: (1) **well-being** factors and (2) **work factors: preparing for, obtaining, and maintaining employment**. Then, we developed guide content within each factor and employment phase to facilitate knowledge building about the client.



Well-being emerged from the phase one survey results and literature as a key component underlying successful employment for adults with FASD. The well-being section includes content about stability and basic needs, family and friends, mental health, legal issues, and children and dependents.

Work factors were divided into employment phases:

- a. **Prepare** for employment, which includes employability skills (communication and social skills, stress management, time management, self-advocacy, and teamwork) and job fit (career goals and interests, psychological assessment, training and education, and workload).

- b. **Obtain** employment, which includes job search (avenues for job searching, job application and preparation), employability skills, and job fit.
- c. **Maintain** employment, which includes job fit, employability skills, relationships (between client and employer, client and employment professional, and employment professional and employer), and conflict resolution.

COMMUNITY COLLABORATION (December 2017 to March 2018)

Community Collaboration Part 1. During the initial drafting of the guide, we collaborated with three community agencies in Alberta for input regarding format and framework of the guide (e.g., well-being factors and work factors), item content, and recommendations for the frequency and preferred method for completing the guide (see Appendix B). This step allowed us to move forward with the guide knowing that the content was relevant and organized in a way that would be valued by employment professionals working with individuals with FASD. This step also helped with forming partnerships for later validity testing of the guide.

Collaborators. We worked with staff from the Lakeland Centre for FASD in Cold Lake, The Alex – Community Health Centre in Calgary, and REDI Enterprises in Medicine Hat.

Responding to Community Feedback. Feedback from members of these organizations led to the revision of several key aspects of the guide, including:

Guidelines for using the guide. Collaborators recommended adding introductory information about how to use the guide and how to collaborate with professional supports to ensure information provided by the client is accurate and leads to the most helpful accommodations.

Flexibility and frequency. Collaborators indicated that how often they complete the evaluations would be different from client to client. We added information to the introduction about being flexible with regard to the frequency and intervals between check-ins.

Relationships. Collaborators shared that a key piece of their role is being a point of contact with the employer, and navigating conflict resolution between the employee and employer. We restructured the original section on relationships and added knowledge building material around conflict resolution.

Community Collaboration Part 2. After making the above changes to the guide, we connected with additional employment professionals supporting individuals with FASD. The purpose of this step was to ensure that the revised guide was not only evidence-based, but also useful for the employment professionals it was designed for. To this end, we had frontline employment professionals supporting adults with FASD use the guide with their clients and complete a survey about the guide's utility (e.g., would you use this guide in the future?), feasibility (what would make it work better?), and validity (does the guide help you evaluate your client's well-being?) (see Appendix C).

The community survey was developed to gather information that could lead to formative changes to the guide. Broadly, we asked closed- and open-ended questions about what they liked and disliked about the guide, what changes could be made to meet their needs, whether the organization of the guide made sense, whether they would use a tool like this in the future, whether they thought the well-being and work factors were important, and whether the guide helped them to evaluate these factors.

Collaborators. We recruited employment professionals through our FASD Learning Series presentation (see Phase Two Knowledge Dissemination), contacts provided to us by Inclusion Alberta, and our earlier partnership with LCFASD, The Alex, and REDI Enterprises.

We distributed the guide and community survey to 24 contacts. We asked employment professionals to complete the survey after using the guide with one or more clients with FASD. Nine employment professionals completed the survey from seven organizations: Accredited Supportive Living Services Ltd., Camrose Association for Community Living, LCFASD, Rehabilitation Society of Southwestern Alberta, The Alex – Community Health Centre, Catholic Social Services, and BRIDGES Hinton.

Responding to Community Feedback. Community collaborators shared valuable feedback that mainly supported the guide, but also informed revisions to the guide to make it even more useful for them in their work.

Almost everyone (89%) agreed that the organization of the tool made sense and the majority (66%) would like to use a tool like this in the future. They responded in agreement that it is important to evaluate well-being, employability skills, job fit, and relationship and conflict resolution, and that this guide was effective for evaluating these factors.

Feedback from the surveys about formative changes to the guide is summarized as follows:

Overcoming barriers. There were concerns among employment professionals that some clients would not move on to begin the job search if the professional waited for all of the items to be completed. To address this, we added further clarification in the introduction prompting them to only complete items that are relevant or feasible and make sense for the agency and client. We also added in a statement on the introduction well-being page that specified that the decision to move between phases is a judgement call to be made on a case-by-case basis.

Employment professionals are looking for solutions. There was feedback asking for more solutions and information about what could be done to help increase the job fit or employee's skills. This request suggests future work can be done to collect and distribute more concrete and illustrative examples of how to develop individualized strategies responding to the client's unique strengths and weaknesses.

The following general themes emerged from the feedback about what employment professionals liked about the tool:

Employment professionals value the well-being of their clients. The well-being factor was well-received and the feedback supported having well-being as its own section to be repeatedly evaluated throughout the process.

"I liked the Well Being portion of the tool. Not many of my clients are at a place in their lives where they are ready for employment. As much as they would like to work they have other factors such as addictions and mental health issues to sort out first."

Promoting understanding. In addition to providing a means of evaluating client goals and progress, employment professionals shared that the tool generated a reflective process to think about their client and their work.

"It gave me a chance to reflect on each of the different factors so I didn't feel like I was missing something. Also, each time I used the tool it reminded me of how I could be misconstruing the participant's behaviour and it allowed more understanding to the participant on my part."

"Creates thoughts and conversation."

*"Pointed out several things to consider when helping someone find employment.
I also liked the plan to work on the items that needed more work."*

Employment professionals like structured and standardized guidance. Feedback from employment professionals suggested that the organization of the guide and the inclusion of forward-focused action guides were relevant for their work.

*"The tool is standardized and has aspects that are measurable, agreed upon,
relevant and timely"*

"I like the action plans, and I like the prompts that the tool provides"

"How easy it is to follow and the relevant information it asks"

PHASE TWO KNOWLEDGE DISSEMINATION

Makela, M., & Kapasi, A. (2018, February). *Supporting Employment Success in Adults with FASD: Employment Study Results and Tool Development*. Oral presentation for the Alberta FASD Learning Series. Edmonton, AB.

The FASD Learning Series helps individuals with FASD and their caregivers to learn more about FASD and about how to support a person with FASD. The webcast and videoconference educational sessions cover a broad range of topics that target both urban and rural audiences.

In this presentation, we shared the program of research leading up to the development of the guide. In sharing the draft of the guide during the presentation, we were able to connect with additional contacts in the field who wished to take part in the validity test.

Presentation available online at:

csslearningseries.ca/learning_series/supporting-employment-success-in-adults-with-fasd/

Makela, M., Kapasi, A., Pei, J., & McFarlane, A. (2018). *Supporting Employment for Individuals with FASD: Guide for Employment Professionals and Final Report*. PolicyWise for Children & Families in collaboration with the Canada FASD Research Network and the University of Alberta.

KEY MESSAGES AND NEXT STEPS

We thank all the families and individuals with FASD, employment professionals, and organizations who shared their wisdom and experience with us throughout this project.

An overarching finding throughout this project was that individuals with FASD can and do experience employment success. Although their employment path may not be a typical one, individuals with FASD are able to work successfully when job fit is appropriate, and relationships are nurtured. Moreover, individuals with FASD and their caregivers possess insight and awareness of the ways in which job fit and relationship can be tailored to best fit the needs of each individual – working with our clients to identify and implement strategies provides us with an ideal path forward. Knowing this, we have appreciated the stories that have been shared with us and it is through these stories that pathways to success are paved.

In support of a collaborative process to identify and implement employment strategies, we have produced a guide to facilitate the process of understanding and responding to areas of strength and need for every individual. We recognize that the guide we produced is not a how-to manual or resource of step-by-step strategies. Instead, we invite employment professionals to engage in a guided reflective process that generates insight about their practice while also addressing client goals and needs.

Finally, this project reflects an important step forward, but is not yet the whole picture. Ongoing information collection and solution generation is required. To this end, we would recommend that next steps include bringing together people invested in supporting the employment goals of individuals with FASD for a joint meeting on FASD and employment. It is clear that adults with FASD and their employment professionals were an integral part of this project. Adults with FASD and their supports are our best source of information, and sharing their experience and wisdom could benefit other employment professionals and their clients. Focused discussions would allow for knowledge sharing of strategies, successes, challenges, solutions, resources, and recommendations. These discussions would serve to:

- Build capacity and collaboration among employment professionals supporting individuals with FASD.
- Engage employment professionals in a process of solution-focused problem solving for individualizing strategies based on their clients' unique strengths and challenges.
- Evaluate the effect of the guide on the employment professionals' reflective practice and client outcomes.
- Empirically investigate the services and interventions used to support employment, work towards best practices for FASD and employment, and include these practices with the guide in a comprehensive FASD and Employment toolkit.

In conclusion, by speaking directly with individuals with FASD and working with the people who support them, we have illustrated that employment success is possible for individuals with FASD. We hope this work will guide more people towards successful employment and positive well-being.

"I learned that my work is valuable" – Adult with FASD



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Appendix A: Employment Success Survey

Employment Stories from People with FASD: Success, Hope, and Possibility

Information and Consent

Some people with Fetal Alcohol Spectrum Disorder (FASD) have a hard time finding good jobs that make them happy. We don't know much about the positive experiences people with FASD have with work.

You are being asked to be in this study because:

- You are 18 years or older
- You have been diagnosed with FASD
- You have a job
- Your family member, mentor, or friend may have heard about the study and asked you to participate

With this study, we want to know about:

- What kinds of job successes are possible for people with FASD
- How people with FASD find good jobs and do well at work
- Different kinds of successes stories from people with FASD who are working

Purpose:

- We are asking adults with FASD and their support people to tell us about the good things and hard things that people with FASD deal with at their jobs.
- We hope to use what we learn from this study to teach employers and programs how to help find good jobs for people with FASD.

Study Details:

1. Take Our Survey

- You will complete a short (30 minute) survey about employment success.
- You can complete the survey on the computer, on paper, or over the phone. If you complete the survey on paper, we will give you an envelope to mail it back to us.

2. Share Your Story

- If you live around Edmonton or Vancouver, or are going to the International FASD Conference in Vancouver (March 2017), there is another part of the study you might want to do.
- We will record a short (10 minute) video of you answering a few questions.
- We will meet you somewhere that's easy for you to get to – close to your home or at the International FASD Conference hotel (Vancouver).
- These stories will be put on the Internet and shared with other people. We will not use your real name in the video. If you don't want people to know it's you, we can record only your voice – not your face.
- The videos will be put together in an online "book," on social media, or other websites.
- We will send the final video to you before we share it, to make sure you're happy with how your story was told. If you decide that you don't want your story used anymore, you can tell us and we will take it out of the video. There is no limit to when you can ask us to take out your story.
- **This part is optional. You don't have to do it. You can choose to do only the survey and not the video.**

Benefits:

- You might like thinking about your job and what is going well for you.
- The information we get from this study might help us understand what adults with FASD need to be successful at work.
- This study won't cost you anything. To thank you for doing the study, we will send you a \$10 gift card.

Risks:

- We don't know of any risks to being in this study.
- If we learn anything during the research that may change your desire to be in the study, we will tell you right away.

Voluntary Participation:

- You do not have to be in this study. Your participation is completely your choice.
- You can skip a question if you do not want to answer it.
- You can change your mind and stop the survey or video at any time.
- After you finish the study, if you decide you don't want to be in the survey anymore, we can delete your information until May 1, 2017.

Confidentiality & Anonymity:

- We will put everyone's survey answers together so no one can tell which answers are yours.
- Your answers will be kept confidential (private) on a computer with a password, or in a locked room in the researchers' office. Only the researchers will be able to look at your answers. Your information will be kept safely for 5 years and then we will delete it.
- The things we learn in this study will be used in research papers, presentations, web postings, and tools for employers and work programs.
- No one will know you took the survey. Other people might be able to recognize you if you choose to do the video.
- When we are done the study, you can look at the findings at www.CanFASD.ca.
- If you want us to send you a short report about what we learned, you can give us your contact information at the end of the survey and we will send it to you.

More Information:

If you have any questions about this study, you can contact:

- Dr. Jacqueline Pei at 780-248-1167 / jpei@ualberta.ca **OR**
- Dr. Katy Flannigan at katy.flannigan@canfasd.ca

This study has been reviewed by a Research Ethics Board at the University of Alberta to make sure it fits with ethical guidelines. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at 780-492-2615. This office has no direct involvement with this study.

I have read or been read this form. The study has been explained to me. I have had a chance to ask questions and my questions have been answered. I have been told whom I can contact if I have more questions. I agree to participate in this study.

Yes

No

I am (please check one):

An adult with FASD

A caregiver for an adult with FASD

A service provider for an adult with FASD

Do you want to share your personal story with other people?

If you live around Edmonton or Vancouver, or are going to the International FASD Conference in Vancouver (March 2017), we can take a video of you talking about your job.

YES. The researchers can take a video of me answering questions about my job.

NO. I only want to do the survey, not the video.

If you want to be in the video, please tell us how we can contact you. Write your name and phone number or email address here: _____

Tell us about your job

Where do you work? _____

What things do you do at work? _____

How long have you worked there?

- 0 to 6 months
- 7 months to 1 year
- 1 year to 5 years
- 6 years to 10 years
- More than 10 years

About how many days do you work each week?

- Less than 1 day
- 1 to 2 days
- 3 to 4 days
- 5 days or more

The number of days I spend at work is:

- Not enough
- Too much
- Just the right amount of days

About how many hours do you work each day?

- 1 to 3 hours per day
- 4 to 6 hours per day
- 7 to 9 hours per day
- 9 hours or more per day

The number of hours I spend at work is:

- Too many
- Not enough
- Just the right amount of hours

What do you do on your breaks (coffee, lunch)? _____

Has your job changed since you started?

- No
 - Yes. *Tell us how it has changed:* _____
-
-

Finding your job

How did you get your job? _____

Was it hard to find a job?

- No
 - Yes. *Tell us why it was hard:* _____
-
-

Did you have any special training to get ready for your job?

- No
 - Yes. *Tell us what kind of training you needed:* _____
-
-

Have you ever lost a job?

- No
 - Yes. *Tell us why you lost your job:* _____
-

Successes and challenges at work

What do you like about your job? _____

What have you learned at your job? _____

How do you know you're doing a good job? _____

What kinds of things are hard at work? _____

If you could change something about your job, what would that be? _____

Your boss and coworkers

What do you like about your boss? _____

What would you change about your boss? _____

What do you like about your coworkers? _____

What would you change about your coworkers? _____

Do you go to work events, like Christmas parties or staff BBQs?

Yes

No. *Tell us why you don't go:* _____

Things that help you with work

Do you need help with any of these things when you're getting ready for work? Check all of the things you need help with:

Waking up

Getting dressed

Eating breakfast

Packing lunch

Other. *Tell us what else helps you:* _____

How do you get to work? _____

Do you need someone to take care of your kids while you work?

No

Yes. *Tell us who takes care of them:* _____

Do any of these help you while you're at work? Check all things that help you:

Lists to remind you what to do

Reminders/alarms to keep you on time

Someone who explains things to you

Someone who helps you with paperwork and filling out forms

Following the same routine every day

Other. *Tell us what else helps you:* _____

Do any of these people help you with work? Check all of the people who help:

- Family
- Friends
- Support worker/job coach
- Role models at work
- Other. *Tell us who else helps you:* _____

How do these people help you with work? _____

Do you talk about your FASD diagnosis at work?

- Yes
- No. *Why don't you talk about FASD at work?* _____

If you do talk about FASD at work, how has it helped? _____

What do you want your boss/coworkers to know about FASD? _____

Pay and benefits

Does your boss pay you to work?

- Yes
- No

Does any other agency pay you to work? (example – Opportunities Fund or Ready, Willing and Able)

- No
- Yes. *What agency pays you to work?* _____

Do you get benefits at work? Check all that apply:

- Paid vacation time
- Health coverage
- Dental coverage
- I don't know
- Other. *What kind of other benefits?* _____

Tell us a bit more about you

How old are you? _____

What is your gender?

- Male
- Female
- Prefer not to say
- Other: _____

What province or state do you live in? _____

Thank you!

You finished the survey!

We would like to send you a \$10 gift card to thank you for being in our study. Please choose either Tim Horton's or iTunes and give us your mailing address.

- Tim Horton's
- iTunes

Write your mailing address here so we can send your gift card. We will delete your address as soon as we mail the card. _____

Appendix B: Questions for Community Employment Professionals

First, thank you for taking the time to provide your valuable feedback on this tool. The purpose of this tool is help professionals evaluate their work and progress in helping adults with FASD become and stay successfully employed in a way that is individualized to their strengths and needs. Your collaboration will ensure we develop a tool that is both evidence-based and useful for you and your peers. We have a few targeted questions for you as you review the tool, and we also welcome any feedback you have outside of these questions. You may add track change comments to the document, or provide comments in this document, or both – whichever is easier for you.

1. What format would you prefer to use this tool once it is finalized and ready for use as part of your regular job?
 - a. Printed paper?
 - b. Update a word document?
 - c. Survey monkey format?
 - d. Phone/ipad app?
2. After we revise the tool based on your feedback, we will be doing a trial run of the tool and collecting the data to inform further changes. With that in mind, what format would you suggest is best for ease of completing as well as sending the data to us?
3. How often do you envision yourself completing the evaluations?
4. Do the categories of prepare, obtain, and maintain make sense based on your experience? Is the tool formatted in a way that works for clients who may transition forward and backward between the stages? We recognize that clients may want to obtain a job even if you determine they are not prepared, and wonder whether you still see this tool being useful in that situation.
5. What resources would you like to see attached to this tool?

We welcome feedback on items and wording as well. Thank you again for your time and participation – we hope this becomes a valuable addition to your work and appreciate any feedback you have about how to make sure it is useful to you and your clients.

Appendix C: Phase Two Survey Questions

- A. What organization do you work for?
- B. How many clients did you use the tool with?
- C. I would like to use a tool like this in my work in the future (yes/no)
- D. What I liked about the tool (open ended):
- E. What I disliked about the tool (open ended):
- F. The organization of the tool makes sense (e.g., well-being factors and work factors, progression from prepare to obtain to maintain) (yes/no)
- G. To meet my needs, I would make the following changes to the tool (open ended):

5pt Likert scale questions:

1. Evaluating my client's wellbeing is helpful for understanding his or her employment situation.
2. This tool was effective for helping me evaluate my client's wellbeing.
3. Evaluating my client's employability skills is helpful for understanding his or her employment situation.
4. This tool was effective for helping me evaluate my client's employability skills.
5. Evaluating my client's job fit is helpful for understanding his or her employment situation.
6. This tool was effective for helping me evaluate my client's job fit.
7. Evaluating my client's relationships and conflict resolution skills is helpful for understanding his or her employment situation.
8. This tool was effective for helping me evaluate my client's relationships and conflict resolution skills.