AN ENHANCED EMPLOYMENT GUIDE FOR EMPLOYMENT
PROFESSIONALS WORKING WITH INDIVIDUALS WITH FETAL ALCOHOL
SPECTRUM DISORDER

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Report Prepared By:

Marnie Makela, PhD

Aamena Kapasi, MA

Vannesa Joly, BA

Jacqueline Pei, PhD

Audrey McFarlane, MBA

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PROJECT VALUE STATEMENT

This project has been shaped by the contributions of service providers, caregivers, and individuals with FASD, all of whom described the many strengths, skills, and abilities that individuals with FASD can contribute to society. Together we hold the belief that successful employment is possible for individuals with FASD. Therefore, this strength-based project focuses on the ways in which we can build capacity in employment professionals and support teams, equipping them with practical and meaningful tools to aid them in their work with individuals with FASD.

EXECUTIVE SUMMARY

Employment serves many goals. It provides an income, opportunities to connect with others, a way to develop oneself, and can increase self-esteem and quality of life. Employment offers a socially valued role, which can be especially meaningful to individuals with Fetal Alcohol Spectrum Disorder (FASD). For individuals with FASD, employment can act as a protective factor against adverse outcomes, including poverty. Fortunately, with appropriate supports, individuals with FASD have the ability to obtain and maintain employment.

Background literature

Fetal Alcohol Spectrum Disorder (FASD) is a neurodevelopmental disorder that is caused by prenatal alcohol exposure and affects up to 5% of the general population (May et al., 2018). Individuals with FASD have a myriad of physical, cognitive, and behavioural difficulties that can make it challenging to obtain and maintain employment. In a seminal longitudinal study, 79% of adults with FASD reported problems with employment (Streissguth et al., 1996). In the workplace, cognitive disabilities may present as difficulty with attention, memory, switching between tasks, organizing and scheduling, working quickly, or controlling impulses (Green, 2016). It is also common for individuals with FASD to have impairments in social functioning, academics, and physical and mental health concerns (O'Connor et al., 2006; Popova et

al., 2016; Streissguth et al., 1996). All these factors contribute to employment challenges. However, when appropriately supported, individuals with FASD can lead fulfilling lives and make valuable contributions within employment settings.

Prior to this project, researchers with the Canada FASD Research Network sought information regarding issues associated with employment for individuals with FASD. To this end they completed a literature review and interviews with nine employment support programs across Canada serving individuals with FASD. They concluded that a supported employment model, with a focus on achieving integrated employment in which clients receive a range of supports, was a suitable model for clients with FASD who are seeking employment (Green, 2016). In particular, information gathered through the interviews highlighted several factors that promoted employment success, such as using individualized strategies, taking a strength-based approach, and building relationships between support staff and clients, and between the employer and support staff (Green, 2016).

The project

In Alberta, several employment programs exist to support individuals with FASD, and professionals in this field have called for guidance regarding best practices in this area (Green, 2016). In response to this call, the CanFASD Network and their partners launched what has become a four-phase project to better understand the experiences of individuals with FASD, the needs of community employment agencies, and ways in which the combination of this information might inform a systematic approach to supporting individuals with FASD to obtain and maintain employment. These four phases evolved naturally, in response to community identified needs and feedback and in the next four sections these four phases will be described.

PHASE 1: INFORMATION GATHERING AND DEFINING SUCCESS

Employment success study examined the conditions under which individuals with FASD experience employment success and the positive impacts of being employed

PHASE 2: DEVELOPING EMPLOYMENT GUIDE FOR FASD

Created a standardized process for assisting employment professionals help clients with FASD prepare for, obtain, and maintain employment

PHASE 3: EMPLOYMENT INITIATIVE MEETING

Brought together stakeholders invested in employment success for individuals with FASD to enhance the guide and build capacity

PHASE 4: ENHANCING THE EMPLOYMENT GUIDE FOR FASD

Revised the guide to reflect key messages gained from attendees of the Employment Initiative meeting

First, we undertook efforts to better understand employment success in adults with FASD (Phase 1, April 2017), and then used this understanding to create an employment guide for assisting employment professionals working with adults with FASD (Phase 2, April 2018; see Makela, Kapasi, Pei & McFarlane, 2018 for details).

Following a positive response to this document, a third phase was initiated. Specifically, professionals sought additional information regarding the mechanisms of implementation that would facilitate seamless use of the guide in their current practice. In keeping with the collaborative approach to the overall project, employment professionals, caregivers, employment organizations, and government officials were invited to attend an employment initiative meeting (Phase 3, January 2019) to contribute their wisdom and experiences to the final phase.

Results from this meeting are consequently being used to enhance the existing guide with considerations for the implementation of strategies to foster job fit and meaningful relationships (Phase 4, April 2019).

PHASE ONE: HOW ARE WE DEFINING SUCCESS IN EMPLOYMENT FOR ADULTS WITH FASD?

What? In the first step in this project, we gathered evidence about the opportunities of employment success for individuals with FASD. Specifically, we were interested to learn more about employment and FASD using a supported employment lens. The goal was to inform FASD employment support programs, other service providers, policy makers, individuals with FASD, and caregivers about the possibility of success. Stories of success may be unknown, and the aim of this aspect of the project was to give a broader voice to what success can look like in an employment setting for individuals with FASD.

How? We recruited adults with FASD and their caregivers and support professionals to complete a survey about the employment journeys of adults with FASD. The aim of the survey was to learn *what employment success can 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.

Two principle questions informed the survey:

1. Under what conditions are people with FASD successful in their employment?

2. What kinds of positive employment impacts are being achieved by adults with FASD?

We learned. Overall, 29 surveys were completed, and three video interviews were conducted. Frequency and descriptive data were obtained from closed ended questions. Key findings from this data included:

- The majority of adults with FASD in this study were reported to be employed for between one to five years (38%)
- The majority of participants in this study reported that adults with FASD had experienced difficulty finding a job (59%), and even more had lost a job in the past (72%)
- The majority of adults with FASD in this sample were reported to work an appropriate number of days each week (76% of adults) and an appropriate number of hours each day (69% of adults) for their needs
- The majority of participants (66%) reported that adults with FASD in this study chose not to disclose their diagnosis at work
- Almost all participants in this study were financially compensated (97%)

Additionally, analysis of this data revealed four factors that were identified as important conditions of employment success for adults with FASD:

1. Finding the right job fit.
2. Using relational supports, including friends, family, and co-workers.
3. Identifying as having FASD at work.
4. Responding to specific workplace challenges they had by using accommodations.

Finally, respondents provided important information regarding the impacts of employment success for individuals with FASD. Four core success outcomes were identified:

1. Increased autonomy through remuneration.
2. Building self-esteem.
3. Developing social connections.
4. Becoming advocates for FASD.

Implications. When individuals with FASD work in accommodating and supportive environments, they experience opportunities for a variety of positive outcomes. Individuals with FASD in this study were reportedly

finding fulfillment and enjoyment at work, and their stories promoted a message of hope and possibility (Kapasi, Makela, Joly, Flannigan, & Pei, 2019). We determined that the question is not *if* individuals with FASD can have employment success, it is *how,* and it became clear that employment success is a shared responsibility of the individual with FASD, the employment organizations, and the community. However, we were also made aware of the complexity of supporting an adult with FASD in their employment journey, and that to do so a resource is needed to help guide employment professionals and communities in their support of individuals with FASD.

PHASE TWO: DEVELOPING THE EMPLOYMENT GUIDE FOR FASD

What? Following the employment success survey, we entered phase two of this project, seeking to further explore the process of how employment success can be achieved for individuals with FASD. To this end, we developed an Employment Guide that provides a standardized process for assisting employment professionals help clients with FASD prepare for, obtain, and maintain employment.

How? The development of this guide was the result of a review of employment literature, existing FASD best practices, the employment success survey results, and collaboration with community employment agencies. Using this participatory approach, we worked to develop a guide that is both evidence-based from the existing literature and grounded in the context of the Alberta FASD community.

Why? 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 obtain and maintain successful employment in a way that is individually tailored to their strengths and needs.

What? 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 sections review the organization of the Employment Guide. Consideration of the role of well-being is emphasized throughout the employment process, and then core aspects of the various factors involved in preparing for, obtaining, and maintaining employment are presented.
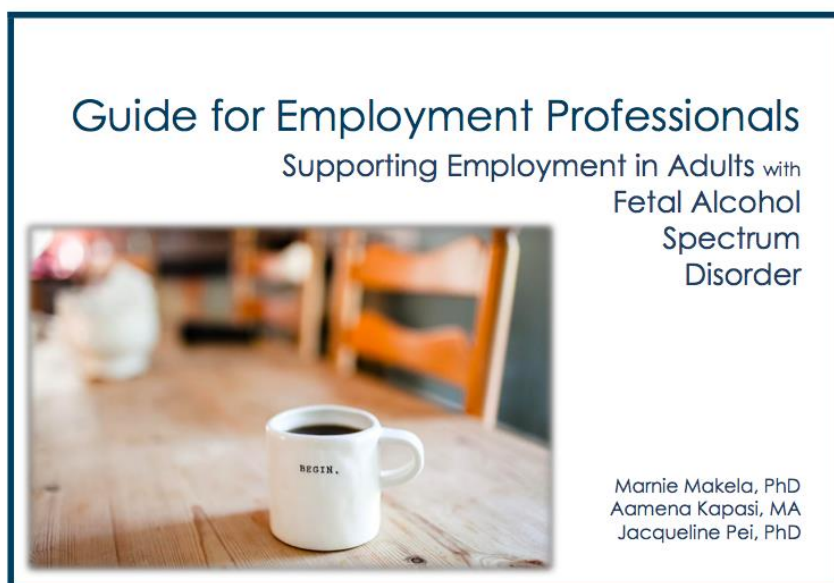

Figure 1. Front page of Employment Guide

Well-being is placed at the forefront of the guide and 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.

WELL-BEING

Well-being Factors		Date	Date	Date	Date	Date	Date
	Insert Date Here ↗						
Stability & Basic Needs	I know if my client has access to appropriate housing	☐	☐	☐	☐	☐	☐
	I know if my client has applied and/or is receiving income support	☐	☐	☐	☐	☐	☐
	I know if my client has access to enough food and nutrition	☐	☐	☐	☐	☐	☐
	I know if my client has access to medical care	☐	☐	☐	☐	☐	☐
	I know if my client has access to recreation activities	☐	☐	☐	☐	☐	☐
	I know if my client has access to an appropriate work wardrobe	☐	☐	☐	☐	☐	☐
Family & Friends	I know of my client's personal support system	☐	☐	☐	☐	☐	☐
	I have connected with my client's guardian or caregiver, if needed (with consent)	☐	☐	☐	☐	☐	☐
	I know whether there are relationship concerns that may impact my client's employment	☐	☐	☐	☐	☐	☐
Mental Health	I understand my client's mental health status	☐	☐	☐	☐	☐	☐
	I understand the stressors in my client's life	☐	☐	☐	☐	☐	☐

Figure 2. Snapshot of some well-being factors from the well-being section from the Employment Guide.

The rest of the guide is divided into three categories: prepare, obtain, and maintain. These were designed to help employment professionals support clients throughout 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.

PREPARE FOR EMPLOYMENT

Employability Skills		Date	Date	Date	Date	Date	Date
	Insert Date Here ↗						
Communication & Social Skills	I understand my client's communication strengths and challenges and how they may impact their employment	☐	☐	☐	☐	☐	☐
	I have made a plan to help my client communicate with others during their employment search	☐	☐	☐	☐	☐	☐
	The communication/socials skills plan was implemented and adjusted as needed	☐	☐	☐	☐	☐	☐
Stress Management	I understand what is stressful for my client and how this may impact their employment	☐	☐	☐	☐	☐	☐
	I understand how my client copes with stress and how this may impact their employment	☐	☐	☐	☐	☐	☐
	I have made a plan to help my client use healthy coping strategies at work	☐	☐	☐	☐	☐	☐
	The plan for coping strategies was implemented and adjusted as needed	☐	☐	☐	☐	☐	☐
Time Management	I understand my client's time management strengths and challenges and how these may impact their employment	☐	☐	☐	☐	☐	☐
	I have made a plan with my client to use time management strategies (e.g., alarm clock, reminders, lists, scheduling transportation)	☐	☐	☐	☐	☐	☐

Figure 3. Snapshot of the employability skills section from the prepare phase the guide.

When clients are in the *obtain* phase, they are looking to gain employment. This category includes job searching, and assessing potential jobs based on the client's employability skills and job fit criteria.

OBTAINING EMPLOYMENT

Job Search		Date	Date	Date	Date	Date	Date
	Insert Date Here ↗						
Avenues for Job Searching	Capitalize on existing connections when possible (e.g., family and friends)	☐	☐	☐	☐	☐	☐
	Review work and volunteer history for positive experiences	☐	☐	☐	☐	☐	☐
	Look for jobs that meet criteria if on income support or other funding program	☐	☐	☐	☐	☐	☐
	Determine the employment type best suited for the client (e.g., supported, sheltered) by reviewing diagnostic/psychology report, funding status, and discussing with client and supports	☐	☐	☐	☐	☐	☐
	Complete and review client's career interest inventory to guide job searching	☐	☐	☐	☐	☐	☐
Job Application & Preparation	I have helped my client prepare a resume and cover letter	☐	☐	☐	☐	☐	☐
	I have helped my client prepare for job interviews	☐	☐	☐	☐	☐	☐
	I have connected my client with resources to assist in preparing a resume and cover letter, and preparing for job interviews	☐	☐	☐	☐	☐	☐

Figure 4. Snapshot of a job search section of the obtain phase from the guide.

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.

MAINTAINING EMPLOYMENT

Job Fit		Date	Date	Date	Date	Date	Date
	Insert Date Here ↗						
Career Goals & Interests	The job continues to fit with my client's employment goals	☐	☐	☐	☐	☐	☐
	The job continues to fit with my client's hobbies and career interests	☐	☐	☐	☐	☐	☐
	The job continues to motivate my client to work (e.g., social engagement, praise, money, contributing, making a difference)	☐	☐	☐	☐	☐	☐
Training & Education	My client has the required level of training and education to continue to work	☐	☐	☐	☐	☐	☐
	I know if there are additional educational opportunities, or if further education is needed, and I have assisted my client in obtaining this education	☐	☐	☐	☐	☐	☐
Ideal # of hours & days of work per week	The number of hours and schedule of the job continues to be appropriate for my client, and if not, I have assisted with the adjustments needed	☐	☐	☐	☐	☐	☐
	I am up-to-date on the other factors in my client's life that influence my client's schedule (e.g., childcare, transportation)	☐	☐	☐	☐	☐	☐
Job Characteristics	The place of employment continues to provide or have accommodations	☐	☐	☐	☐	☐	☐
	The place of employment provides a support person on site if needed	☐	☐	☐	☐	☐	☐

Figure 5. Snapshot of the job fit section of the maintain phase from the guide.

Community Consultation. Upon completion of this document it was distributed to organizations accompanied by a feedback form. This community consultation revealed that the document provided them with an effective means for promoting understanding of their client's well-being, employability skills, job fit, and relationships. They liked the structure and standardized guidance of the guide and the majority stated they would use it in the future, but some noted it could be even more useful and feasible within their work settings if it included more solutions and information about what could be done to facilitate job fit and increase the employee's skills. For more information about the development of the Employment Guide, please see the final report submitted to Policy Wise for Children and Families (Makela et al., 2018).

PHASE THREE: THE EMPLOYMENT INITIATIVE MEETING

August 2018 to April 2019

What? In response to community feedback for *more solutions and information about what could be done to help facilitate job fit* we determined it was necessary to seek specific community-based feedback to inform the evolution of the guide and direct specific implementation recommendations.

How? We organized and conducted a one-day meeting to bring together community partners invested in supporting individuals with FASD and employment. This entailed four key steps:

GETTING STARTED: Developing meeting goals & obtaining ethics approval

ENGAGING COMMUNITY PARTNERS: Collaborating and inviting attendees

IDENTIFYING INFORMATION SOURCES: Developing survey and focus group questions

RESULTS: Analyze key messages & assess meeting impacts
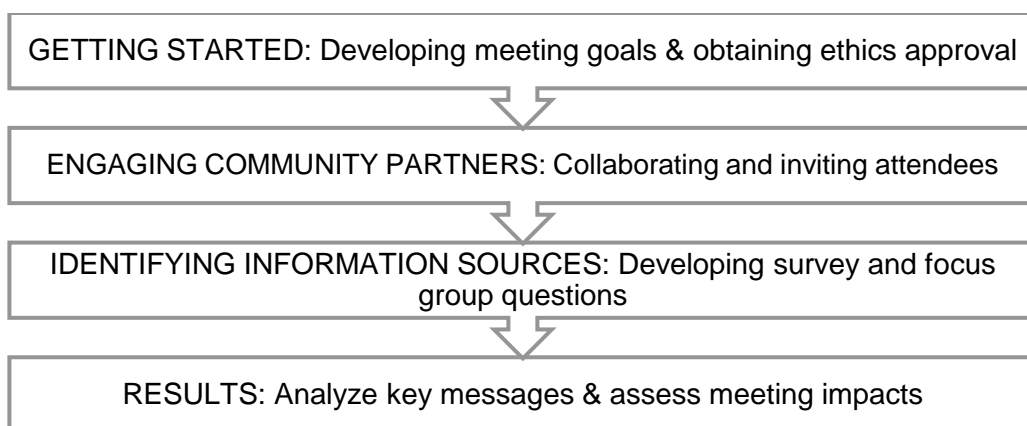
STEP 1: GETTING STARTED

In partnership with the CanFASD Family Advisory Committee we identified the following meeting goals and indicators. Ethics approval was completed through the University of Alberta.

GOAL	WHY?	INDICATOR
Collect data to incorporate additional tools (e.g., strategies, examples, and resources) into the Employment Guide and to inform the use of the Employment Guide in practice.	To build capacity in employment professionals/support teams as they work to improve employment outcomes for individuals with FASD.	The development and distribution of the revised guide to meeting attendees and the larger FASD and employment community.
Provide an opportunity for networking, resource sharing, and reflecting for people invested in seeing individuals with FASD succeed in employment.	To facilitate future collaborative relationships and to increase the number of contacts amongst people supporting individuals with FASD with employment.	Change in ratings of perceived access to networks and resources from pre- to post-meeting survey. Rating of how well the meeting facilitated networking resource sharing and reflecting.
Foster understanding and appreciation of what is involved in supporting employment with individual with FASD.	To create a mutual understanding amongst people invested in seeing individuals with FASD succeed in employment.	Post-event survey of knowledge and appreciation of the processes and combined efforts involved in fostering employment success in individuals with FASD.

STEP 2: ENGAGING COMMUNITY PARTNERS

Our team invited approximately 146 community partners in the area of employment and FASD across Alberta, including community and government agencies, employment organizations, parents and caregivers, individuals with FASD, and the provincial FASD networks. Additionally, the event was advertised through CanFASD's social media accounts and provincial network listservs. We also formed a working partnership with Inclusion Alberta, an organization with connection to caregivers of individuals with FASD to ensure we reached caregivers with our invitation.

STEP 3: IDENTIFYING INFORMATION SOURCES

What? We attempted to gather information in multiple formats before, during, and after the meeting. This allowed us to gather information for the revisions of the guide, assess the impact of the meeting on attendee's networks, resources, and knowledge, and evaluate the meeting. Information sources included a pre-meeting survey, focus group questions, post-it note questions, and a post-meeting survey.

How? Questions were developed in two steps:

 1) Examining statements within the Employment Guide and the themes from the employment success study (Kapasi et al., 2018) that could be elaborated on in more practical or meaningful ways. For example, in the Employment Guide we recommend the employment professional examines the strengths and difficulties in three relationship dyads: Client and Employer Relationship, Client and Employment Professional Relationship, and Employment Professional and Employer Relationship. To further elucidate how to build strong working alliances, we asked, "what is needed for the relationship between the individual with FASD and support person to work well?" and "what is needed for the working relationship between the individual with FASD/support person and the employer to work well?"

2) Seeking feedback from the CanFASD Family Advisory Committee and Inclusion Alberta in order to ensure caregivers perspectives were reflected in the questions.

Once developed, questions were assigned to the pre- or post-surveys, post-it notes, or focus groups depending on the level of depth required to answer the question. For example, questions about specific resources such as training opportunities for individuals with FASD were assigned to the pre-survey and questions that would prompt more discussion such as attitudes and processes were assigned to the focus groups.

Pre- and post-meeting surveys

What? A short online questionnaire was sent to attendees prior to the meeting and included questions on demographic information, employment support practices, and perceptions of access to networks and resources. The outcomes of this survey were used to generate topics of discussion at the meeting (e.g., similarities and differences in experiences, context, knowledge, and beliefs) and to compare pre- and post-meeting ratings of perceived access and ability to support individuals with FASD.

How? Attendees rated themselves on the following three statements before attending the meeting, and then after the meeting:

1. I feel confident in my ability to support individuals with FASD through their employment journeys.
2. I have the necessary resources and networks to support individuals with FASD through their employment journeys.
3. I rate my knowledge of FASD and employment supports and strategies as strong.

Additionally, after the meeting participants were also asked about potential impacts the meeting may have had on their professional and/or personal perspectives. Specifically, we asked about the top 3 things they learned, any surprises from the day, key factors they think

are most important to help the individuals they work with, and how they might use the guide in the future (see appendix 2 for the surveys).

Focus group questions

During the meeting attendees were divided into seven groups. Throughout the day each group was tasked with answering approximately four questions. One overarching question was posed to all groups:

What attitudes and beliefs do you think are really important in a support person/worker to facilitate employment success? What have you learned from employers about what they need in order to best support individuals with FASD in the workplace?

Then, each group was given a second question to answer in the morning and two questions to answer in the afternoon. We chose to give each group a different set of questions to enable us to address as many aspects of the Employment Guide as possible, while maintaining a reasonable degree of depth (e.g., 45 minutes per question and follow-up conversation). Following the focus group sessions, a speaker from each group summarized their group's discussion and shared it with everyone. We led a whole group discussion during which the question was then opened up to the whole room for commentary. This allowed everyone the opportunity to comment on each question while allowing as many different questions to be answered as possible.

The questions for group two are provided below to illustrate the format. See appendix 1 for all of the focus group questions.

Group 2	
Morning	Afternoon
Sharing an FASD diagnosis is a personal decision. How does sharing/not sharing the FASD diagnosis impact the	How could the support person describe their role to the employer? Would this change

conversation with employers around accommodations and supports? How do you decide how much diagnostic information to share with the employer?	when a diagnosis is being shared/not being shared? What would you do if changes in the workplace affect job fit?

Post-it notes

Attendees were also invited to answer three questions anonymously by sticking a post-it note on poster boards around the room. This allowed attendees to consider some topics over the course of the day, add evolving thoughts over the course of the day, and reflect on posts made by others. It also created a space for conversation during breaks that facilitated further generation of ideas.

What does good job fit mean to you?

If you could break down what we learned today into one sentence what would it be?

What are some unique strengths and challenges you experience supporting employment in a/an...

...urban setting?

...rural setting?

...remote setting?
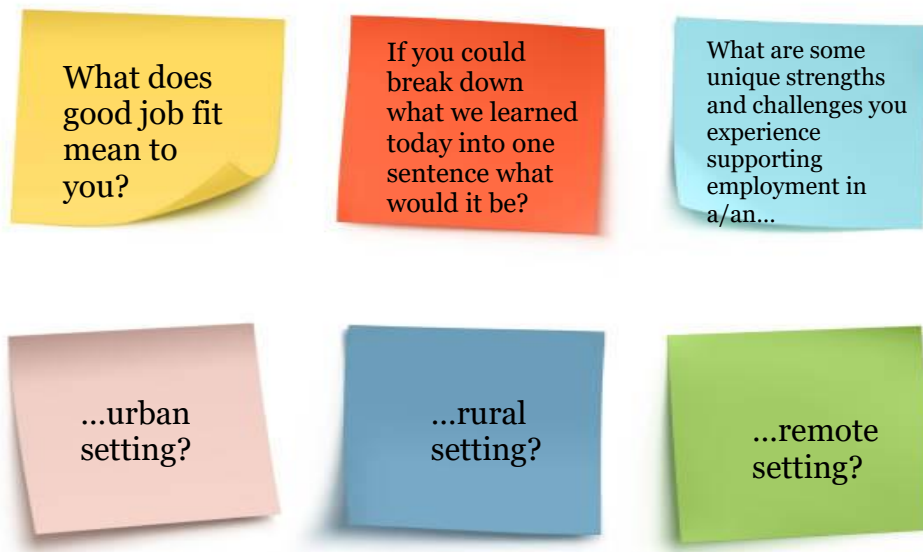
STEP 4: RESULTS

About the attendees

Thirty-six attendees completed the pre-survey and thirty-seven people attended the Employment Initiative meeting. There was a diverse group of attendees present, representing many perspectives.

- 55% of attendees identified having expertise in FASD, 33% identified as having employment expertise, and 12% identified as having both areas of expertise.
- A variety of roles and backgrounds were reported including researchers, mentors, family members, individuals with FASD, job coaches, managers, employment coordinators, policy development and individual support workers.
- The majority of respondents (39%) reported working in a primarily urban context (see figure 6)
- The majority of respondents reported having frequent (daily) contact with an individual with FASD (44%) (see Figure 7).
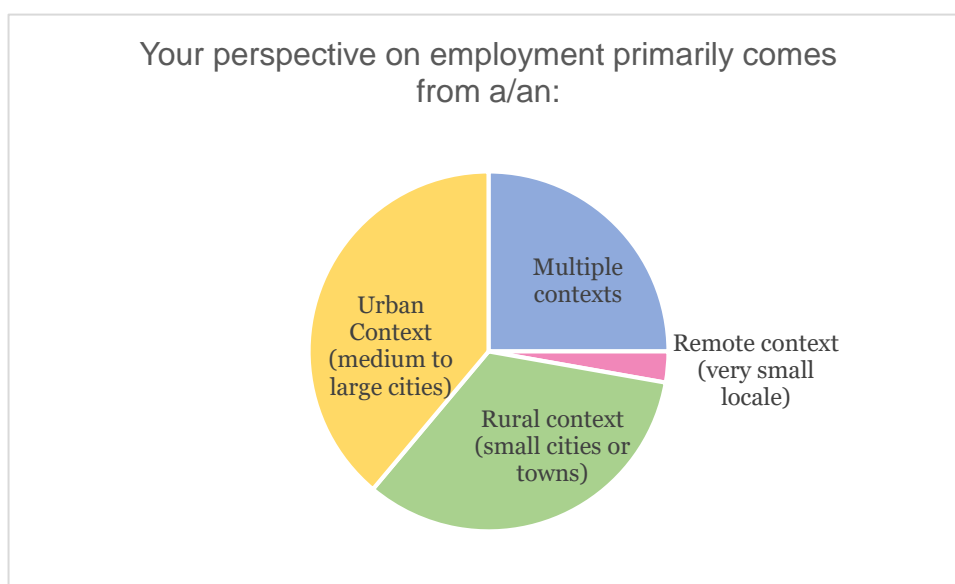
Figure 6. Pie chart showing attendees employment context based on pre-survey results.
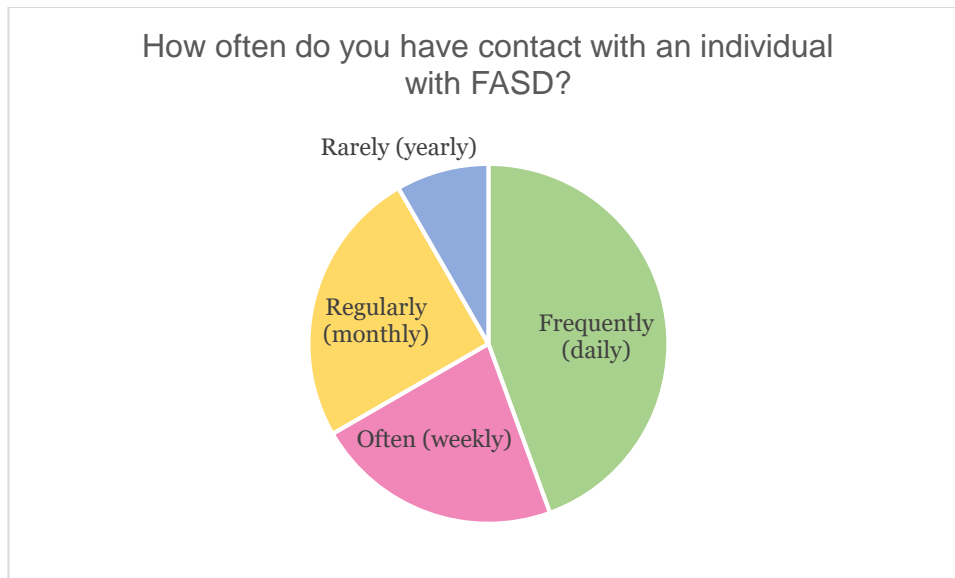
Figure 7. Pie chart showing attendees reported frequency of contact with an individual with FASD based on pre-survey results.

We asked respondents to respond to the following two statements:

1. I believe that individuals with FASD have the **ability** to develop the necessary skills to obtain and maintain paid employment.
   - There was a mix of responses to this question, with majority of respondents agreeing.

2. Individuals with FASD should have the **opportunity** to realize their potential to contribute to their community through work.
   - All respondents either strongly agreed or agreed to this statement.
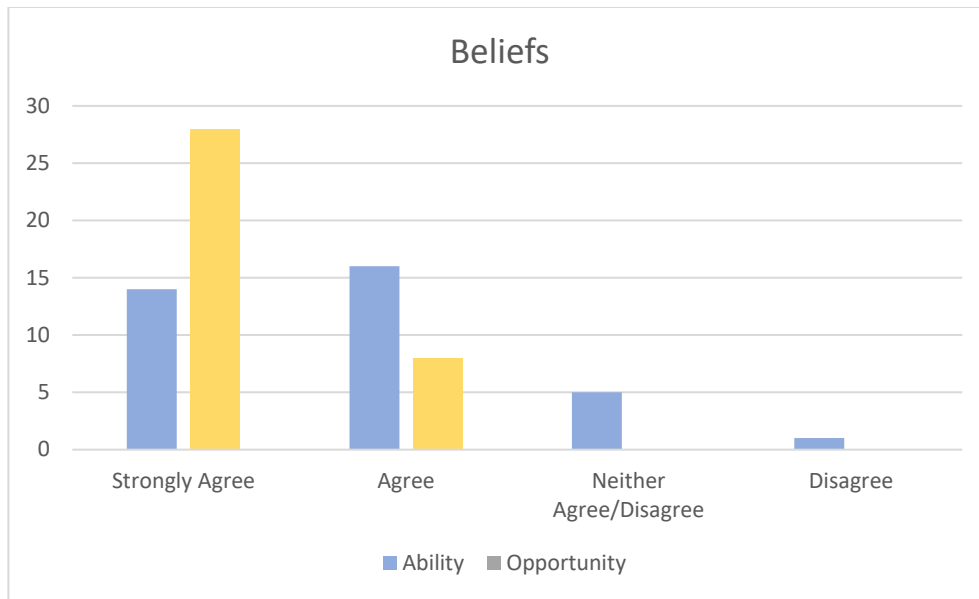
Figure 8. Bar graph showing attendees reported beliefs about the abilities and opportunities for employment for individuals with FASD based on pre-survey results.

It is notable that all participants agreed or strongly agreed that individuals with FASD should have the *opportunity* to work, but some believe that individuals with FASD may not have the *ability* to obtain and maintain paid employment. We take this to reflect the spectrum of abilities inherent in FASD and we acknowledge that employment opportunities will differ according to the individual's abilities and life circumstances. Overall, we feel that the following key messages reflect a diverse and informed group of people invested in seeing individuals with FASD succeed.

Analyzing for understandings

Over the course of the day and across the various data collection methods, attendees shared their perspectives on topics including job fit, relationships, diagnosis sharing, job loss, advocacy, adapting to change, and identifying strengths. After a thorough analysis of the information collected, we identified a number of key messages that will inform a revision of the Employment Guide (Goal #1).

How? Data from the pre- and post-surveys, focus groups, and post-it notes were consolidated and three researchers coded the information

according to four categories: attitudes/values/beliefs; personality characteristics; knowledge and education; and practical strategies. Then, we looked across these categories for common themes or key messages and arrived at the following six key messages: fostering meaningful job fit, what does it take to be an employment professional, collaborating meaningfully, staying a step ahead, normalizing workplace accommodations, and empowering the process.

Fostering job fit

What is a good job fit? We understand job fit as an *interaction* between the *client's individual strengths and needs* and the *context, setting, and requirements of a job*. This was supported by participants who emphasized that a good job fit is "…where both the employee and employer are in good understanding of the responsibilities of each other….but weakness is not treated with scrutiny….respect, accountability, honesty, and hard work are in sync". This appreciation for reciprocity and mutual respect was also described as "a connection of shared interest and skills between client and employer". Participants also emphasized the importance of truly understanding the needs of the individuals they are working with and "…respect[ing] the limitations a person may have…" so that they might be best able to employ "flexibility in being able to adapt certain parts of the job role in order to maximize the strengths…". Ultimately attendees emphasized the importance of "…a job that aligns with your passions and can bring you a sense of accomplishment."

How to achieve job fit. Attendees shared various strategies to achieve the three core components we agreed are necessary to achieve a meaningful job fit: 1) understanding the client's strengths and needs, 2) understanding the context, setting and requirements of a job, and 3) the interaction between these elements.

1) *Understanding the client's individual strengths and needs* was identified as a priority by attendees. They identified several approaches to gathering this information including conversations with the client and with their support network and taking time to observe the client in

different environments. For example, one participant suggested asking potential employers, "can we come and try this for an hour?" as a way to learn how the client does in that work environment. Part of the process of understanding the client is learning how they would like to share their disability with the employer. In our research, we have found that sharing the FASD diagnosis with employers can be helpful; however, we gathered that many people did not share their diagnosis due to fear of discrimination or because they felt they did not need to (Kapasi et al., 2018). Through focused discussions about sharing the diagnosis with employers, attendees first acknowledged that it is important to respect their client's wishes regarding how much or how little to share. With this respect established, they then spoke of helping their client accept and understand their diagnosis and building self-advocacy skills using scripts and role play. They also shared that there are ways to express the client's needs without sharing an exact diagnosis. One attendee explained "They have the right to diverge as little or as much about themselves."

2) Understanding the *context, setting, and requirements of a job* was also identified as a critical component of establishing job fit. Attendees shared that finding the right fit in an employer or direct supervisor is perhaps even more important than finding the right job duties. According to attendees, "when the employer understands the individual with his or her challenges, they seem to work at making it easy for our clients to do the job." We gathered that the employment professional should look for certain values and characteristics in the employer, such as employers who are "accepting," "open to working with individuals with disabilities," and "willing to listen and accommodate." Some employers may possess these values and characteristics on their own, while others may require education about FASD and the benefits of and what is involved with hiring someone with a disability.

3) Fostering a meaningful interaction between the client and employment option was described by attendees as an effective merger of the formerly described points. Attendees shared the need to be creative and "think outside the box" with this match by moving towards job

carving. Job carving refers to the process of creating, modifying or customizing a community-based job such that it can be successfully performed by an individual with disabilities, while also meeting the needs of an employer.

What does it take to be an employment professional?

Attendees shared that employment professionals who are client-focused, not afraid to ask questions, willing to explore options, believe in their client, and communicate with all individuals involved are best able to facilitate job fit and manage the interaction between client and employer needs. Key duties include being a record keeper and an advocate, and maintaining regular contact with the employer through in-person and distance check-ins and formal and informal assessment methods (e.g., checklists/surveys and conversations).

In order to do their job well, attendees described numerous things for employment professionals to *know*, to have *access to*, and to *be able to do*. For example, employment professionals need to *know* the facts behind the business aspects of hiring individuals with disabilities, they need *access* to professional development training to gain this knowledge, and they need to be *able* to effectively communicate about this information with employers to achieve successful outcomes for the client and employer.

As is clearly illustrated below, attendees were able to come up with an extensive set of characteristics that are essential for building strong working relationships with clients and with employers.

Time-management   Proactive

Empathy Mindful

Compassion   Non-judgemental

Creative   Transparent

Communicator   Energetic   Consistent

Available   Listener Networker

Dedicated Cheerleader   Inclusive

Learner Confident   Positive

Flexible   Resourceful Advocate

Proud Adaptable   Sensitive

Dependable Honest   Respectful

Resilient   Boundaries

Caring   Relentless Accommodating

Patient   WordItOut

Collaborating meaningfully

Attendees discussed the importance of reframing the employment
journey as a collaborative process, rather than an individualized success
or failure. Applying what they referred to as the "Q-TIP principle" (i.e.
Quit Taking It Personally) they endorsed a blame free process to
working with individuals with FASD. They endorsed a philosophy in
which the whole team contributes to the employment journey and shares
responsibility for the ups and downs along the way. This team includes
the individual with FASD, their employment professional, employer, co-
workers, and their network of family and friends. There was a shared
sentiment that "by working together, we get increased
knowledge." Moreover, they emphasized that the employment
professional should not only communicate with people who know the
client well, but truly *listen* to these people's perspectives; giving equal
value to all information sources including caregivers.

Staying a Step Ahead

Workplaces are always evolving, and we know that change is especially
hard for individuals with FASD. Attendees shared that a proactive
approach to supported employment can prevent issues from getting out
of hand; however, "more often than not, the changes happen before
we're aware of it." Thus, they emphasize that having a strong

relationship with the employer, established early in an employment placement, is critical to facilitating proactive responses. Ideally, this type of relationship may be supported by having a job coach on site for the first two weeks; however, attendees shared that this is not always possible due to "limited time and resources." Therefore, establishing a working relationship with the employer when the client starts their position and debriefing within the first two weeks can be helpful to identify what works and what doesn't.

Proactive approaches may facilitate job maintenance and in other instances may contribute to more supportive job dismissals that are conducive to future learning. Specifically, attendees suggested that employers involve them ahead of changes in the workplace (e.g., managerial changes, dismissals) so they can work with the client to adjust during the transition period, assess and problem solve, and move forward. In our previous research, we found that 71% of survey respondents with FASD had lost a job in the past. Attendees provided ideas for handling job loss, such as using the event as an opportunity to foster growth and change by re-framing failure as trial and error; seeking ways to involve support people in the dismissal process may help facilitate this learning.

Furthermore, we know that consistency, routine, and structure are often important factors in employment success for individuals with FASD and being proactive in maintaining the necessary level of support and environmental accommodations amidst inevitable workplace changes is going to contribute to success for clients.

Normalizing workplace accommodations

The provision of workplace accommodations is not only a right for individuals, but can contribute to employment success by responding to specific challenges the individual faces (Kapasi et al., 2018). Attendees emphasized that it is important that these supports are seen as ways to help facilitate access to areas of strength, and as long-term supports not to be removed when the client is demonstrating success.

Attendees considered what it means to reframe accommodations and to describe them as normal ways to address an area of difficulty in order to access a strength. Applying approaches that reduce stigma, one attendee provided a comparison to her need for glasses. Attendees agreed that glasses do not diminish an individual's contribution but are required for that individual to access their capacities.

Similarly, this same illustration informed conversation regarding the need for long term supports underscoring that accommodations are "not a phase out thing and these supports need to be here always." Attendees shared about

Empowering the process

In line with our project's underlying value statement, attendees discussed the importance of a strength-based approach and building on strengths and interests, empowering their client, and recognizing that all individuals have contributions to make to the workforce. It was important to attendees that clients "realize how capable they are" and understand that "success means different things." Ways to empower the client to continue on their employment journey include taking time to consider what is motivating the client, from preparing for employment, beginning to search for a job, and maintaining a job. Attendees noted that it may be helpful to identify rewards other than just the job or paycheck (e.g., friends), set small rewards to keep individuals engaged, and "celebrate and acknowledge what makes individuals important at their job."

Meeting impacts

Networks and Resources. In addition to the core themes identified through the collaborative and reflective discussions, attendees also identified that the meeting itself was beneficial to them. Specifically, they reported an overall increase in resources and network access, from an average of 5.11 before the meeting to 6.31 after the meeting on a scale of 1 (strongly disagree) to 10 (strongly agree). Attendees also reported an average rating of 8.8 on a scale from 0 (ineffective) to 10 (effective)

when asked about how well the meeting facilitated the opportunity to network, share resources, and reflect with others invested in seeing individuals with FASD succeed in employment.

Knowledge and Confidence. Attendees reported an overall increase when asked about their knowledge of FASD and employment supports and strategies, from 5.83 before the meeting to 7.58 after the meeting on a scale of 1 (strongly disagree) to 10 (strongly agree). Attendees also reported an average rating of 8.8 on a scale from 0 (ineffective) to 10 (effective) when asked how well the discussions during the meeting increased their knowledge and appreciation of the processes and combined efforts involved in fostering employment success with individuals with FASD. Overall, attendees reported an increase in confidence in their ability to support individuals with FASD through their employment journeys after the meeting, from 6.50 before the meeting to 7.58 after the meeting.

Meeting feedback

When asked how well the meeting was organized and conducted overall on a scale from 0 (ineffective) to 10 (effective), attendees endorsed an average of 9.25. When asked for comments about the meeting, many attendees shared their appreciation for attending the meeting. Three common themes of feedback emerged: 1) mixing the composition of the morning and afternoon focus groups so people could change groups and share ideas with new people, 2) engaging employers and bringing them to the table, and 3) using audio recording instead of note taking in the focus groups. In general, the comments from the meeting were positive and indicated we were successful in our goals to provide an opportunity for networking, resource sharing, and reflecting, and to increase understanding of what is involved in fostering employment success with individuals with FASD.

We were also interested in how attendees planned on using the Employment Guide in their practice and attendees shared that they would use the Employment Guide in multiple ways. Attendees reported that the guide "informs the process that should be used" and highlighted

its use for information gathering to ensure all areas of need are addressed. They also reported that the guide provides ideas for how to best support individuals with FASD, and can be used to understand clients better, motivate clients, and identify areas of success and need. Attendees also reported they would use the guide because it is a great resource to keep the employment professional focused and on track. Attendees reported that the guide can be helpful in reflecting when developing a service delivery plan. Additionally, attendees reported that they would share the guide with colleagues and use it with clients of all disabilities, not just those with FASD.

Summary

The Employment Initiatives meeting was geared to achieving three goals: inform the evolution of the Employment Guide, create an opportunity for networking and resource sharing, and to increase understandings of what is involved in fostering employment success for individuals with FASD. The data we collected at the Employment Initiatives meeting was from key stakeholders invested in seeing individuals with FASD experience employment success. The attendees provided us with first-hand experiences and practical recommendations for fostering meaningful job fit, collaborating meaningfully, staying a step ahead, normalizing workplace accommodations, and empowering the process. These key messages and the practical recommendations will be used to enhance the Employment Guide.

The Employment Initiatives meeting also served as a capacity building opportunity and attendees positively endorsed the impact of the meeting on their access to resources and on their knowledge and confidence in their roles. We are encouraged that this meeting increased attendee's understandings of what is involved in fostering employment success for individuals with FASD and that attendees looked forward to implementing what they learned and sharing the resources with their own networks, further extending the reach and impact of this project.

PHASE FOUR: ENHANCING THE EMPLOYMENT GUIDE FOR FASD

Using the information we collected from the Employment Initiative meeting, we are enhancing and refining the Employment Guide to incorporate the perspectives we gathered and offer more strategies for meeting the needs of individuals with FASD who are seeking employment. We anticipate sharing the final Employment Guide 2.0 with attendees and the larger community in Summer 2019. Please see the attached Employment Guide 2.0 for highlights of the changes we are making. Some of the changes include:

> Adding an identity subcategory to help employment professionals better understand if and how their client would like to identify their disability in the workplace
> Enhancing the section on job fit to include information about how to gather information about the client and connecting with employers
> Placing more emphasis on a team approach and interacting with the caregiver and family of the individual with FASD
> Highlighting the importance of being proactive and offering strategies
> Including information about motivating the client
> Adding reflective chart for the employment professional about what they need to know and be able to do
> Increasing the employer relationship section to include more suggestions and strategies

We anticipate these changes will improve the practicality and usefulness of the guide and go beyond providing information on *what* to do to, adding more information about *how* to do it.

PUBLICATIONS AND KNOWLEDGE DISSEMINATION

Kapasi, A., Makela, M., Joly, V., Flannigan, K., & Pei, J. (In Press). Understanding employment success in adults with Fetal Alcohol Spectrum Disorder. *Journal of Vocational Rehabilitation*.

Kapasi, A., & Joly, V. (Accepted; June 2019). Supporting Employment in Adults with FASD: A Guide for Employment Professionals. Oral Presentation. The Canadian Association for Support Employment, Montreal, Canada.

Kapasi, A. (March 22, 2019). Engaging Cognitive Diversity in the Workplace. Equity, Diversity, Inclusion Week. University of Alberta, Edmonton, Alberta.

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.

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.

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.

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.

CONCLUSIONS AND MOVING FORWARD

We engaged with many invested, collaborative, and positive stakeholders throughout this project and we owe our gratitude to the many individuals who contributed their time, effort, and perspectives to the employment success study, development of the Employment Guide, and Employment Initiatives meeting. We are encouraged by the many ideas for application of the Employment Guide and look forward to sharing the revised version with attendees and the larger community. Opportunities to conduct follow-up evaluation of the implementation of the guide would serve to inform the impact of the current project and measure the outcomes of the guide's use.

We have gathered many perspectives on how to foster employment success for individuals with FASD, but the work in this project has not yet explored the experiences and perceptions of current or prospective employers of individuals with FASD. Our messaging and guide content positions employers as central to fostering successful experiences and we believe that we could gain valuable insight by including employers and co-workers in conversations about job fit, collaboration, working proactively with supports, implementing accommodations, and motivation. Mobilizing this information would allow service providers and support networks to better support individual with FASD.

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Appendix 1

Focus Group Questions

Group 1	
Morning	Afternoon
In many communities, there are only so many jobs available. How do you balance the importance of finding a workplace that will have good job fit with the need to have a job?	Different people will succeed in different workplaces. How do you determine that a workplace is appropriate for you or the person you are supporting? What is needed for the relationship between the individual with FASD/support person and the employer to work well?

Group 2	
Morning	Afternoon
There are many reasons why it might be hard for an individual with FASD to find a job. What have you learned along the way about navigating these challenges? What changes if you or the person you are supporting has a criminal record or legal issues, such as children services involvement?	What could you do when you or the person you are supporting is not prepared for employment based on the well-being assessment, but they need to work (e.g., for financial, court ordered, or personal reasons)? What is needed for the working relationship between a support person and an individual with FASD to work well?

Group 3	
Morning	Afternoon
Some individuals with FASD have told us that they have found ways to use their challenges to their advantage in the workplace. How do you re-frame	How could you help the individual with FASD start using accommodations (e.g., reminders, lists, breaks) at their job and how could you assess that these strategies continue to work for them?

challenges as potential opportunities for employment?	How might someone help the person they are supporting build self-advocacy skills in the workplace?

Group 4	
Morning	Afternoon
Many people have difficulty finding a job. How do you help the person you are supporting stay motivated during the job search?	How could you work with the employer to find the right accommodations for the needs of the individual with FASD? How often and how could you re-assess job fit during employment?

Group 5	
Morning	Afternoon
How do previous school or training experiences shape the employment path? How does it inform the type of employment you or the person you are supporting pursues?	How might the role of a support person change when the individual with FASD shifts from preparing for a job to keeping a job? What kinds of questions could you ask to make sure the job is still going well? Who could you talk to?

Group 6	
Morning	Afternoon
Sharing an FASD diagnosis is a personal decision. How does sharing/not sharing the FASD diagnosis impact the conversation with employers around accommodations and supports? How do you decide how much diagnostic information to share with the employer?	How could the support person describe their role to the employer? Would this change when a diagnosis is being shared/not being shared? What would you do if changes in the workplace affect job fit?

Group 7	
Morning	Afternoon
What happens when there are changes in employment supports (e.g., frequent support staff changes)? How do you manage these changes?	How do you identify strengths/abilities/interests/goals/skills to try to find the best job fit for you or the person you are supporting? How could you build on the existing skill set of the person you are supporting? How could you help an individual with FASD share their diagnosis with their workplace? How can you help them do this in a way that advocates for their needs?

Appendix 2: Pre and Post Meeting Surveys

Let's get the conversation started: Employment & FASD

You have been sent this survey as an attendee of the upcoming Canada FASD Research Network Employment Initiative meeting on January 25th, 2019. We are hoping to achieve a greater understanding of what communities and programs are doing to support individuals with FASD through their employment journeys. Specifically, we are seeking your thoughts and experiences about what strategies and supports are involved as individuals with FASD prepare for, obtain, and maintain employment. We're hoping you will all be willing to share your expertise!

To tailor the meetings to the needs of our participants, we ask that you answer the following questions to the best of your ability. Feel free to tell us your thoughts. There are no right or wrong answers - just great points for discussion. Please know that we will not share your personal information with anyone, but we will be sharing overall trends from the survey with the group.

We respectfully thank you for taking the time to complete this survey.

We would like to use the Employment Initiative pre-survey as an opportunity to collect
data for research purposes.
Your thoughts and ideas will help us in furthering our understanding of employment and
FASD. We don't know of any risks to being in this study.
Your participation is completely voluntary. You can attend the Employment Initiative
meeting and not consent for your survey information to be used in the research study. If
you chose to stop the survey before you complete it, your answers will not be used in the
research study. The survey is anonymous, so we will not know which answers are
yours. Please indicate if you consent to your pre-survey answers being used for research
purposes.

- o   I wish for this information to be included in the research study
- o   I do not wish for this information to be included in the research study

Demographic questions
The following questions are to help us get to know you. We've invited
individuals with a range of experiences in both employment and FASD related

fields, and by answering these questions we hope to get a sense of who is in the room on January 25th.

Your area of expertise falls in the domain of:
- Employment;
- FASD;
- Both;
- Other (please specify)

What is your role in supporting an individual with FASD in their employment journey?

Your perspective on employment primarily comes from a(n):
- Urban Context (medium to large cities);
- Rural context (small cities or towns);
- Remote context (very small locale);
- Multiple contexts

How often do you work or have contact with individuals with FASD?
- Frequently (daily)
- Often (weekly)
- Regularly (monthly)
- Rarely (yearly)
- Never

Beliefs: The following questions target more of your beliefs around employment and FASD. In doing so, we hope to establish some context and greater understanding of what you think about these issues.

I believe that people with FASD have the ability to develop the necessary skills to obtain and maintain paid employment.
- Strongly Agree
- Agree
- Neither Agree/Disagree
- Disagree
- Strongly Disagree

Individuals with FASD should have the opportunity to realize their potential to contribute to their community through work. (scale 1-10)
- Strongly Agree
- Agree
- Neither Agree/Disagree

- Disagree
- Strongly Disagree

I feel confident in my ability to support individuals with FASD through their employment journeys. (scale 1-10)
- Strongly Agree
- Agree
- Neither Agree/Disagree
- Disagree
- Strongly Disagree

I have the necessary resources and networks to support individuals with FASD through their employment journeys. (scale 1-10)
- Strongly Agree
- Agree
- Neither Agree/Disagree
- Disagree
- Strongly Disagree

I rate my knowledge of FASD and employment supports and strategies as strong.
- Strongly Agree
- Agree
- Neither Agree/Disagree
- Disagree
- Strongly Disagree

In our work leading up to the meeting, we have come to realize job fit is an important
part of fostering successful employment for individuals with FASD. We understand job fit
as an interaction between the client's individual strengths and needs and the context,
setting, and requirements of a job. What does job fit mean to you?

Challenging and Successful Experiences: The following questions target your experiences in the domains of employment and FASD. In asking these questions, we hope to establish some context and greater understanding of you have experienced while supporting individuals with FASD through their employment journey. We hope that by coming together with these stories, we can find ways to foster more employment successes.

What is the greatest challenge you face when supporting individuals with FASD through their employment journeys?

What are some of your successes supporting individuals with FASD through their employment journeys?

Strategies: The following questions target strategies that you have had experience with in your role supporting individuals with FASD through their employment journeys. We aim to collect these ideas and strategies for resource development and sharing during the Employment Initiative meeting.

What resources have you found helpful to address employability skills (e.g., communication, stress management, time management, self-advocacy, teamwork). For example, online, workbooks, groups, agencies, apps etc.

What training/education programs/courses have you found to be a good fit for this population to increase employability (e.g., certain driving school, life skills)?

What strategies have you used to help individuals with FASD prepare for job interviews (e.g., role play)?

Thank you for completing our pre-meeting survey. We look forward to hearing more of your thoughts during the Employment Initiative meeting January 25th, 2019.

CanFASD Employment Initiative: Post-Survey

Thank you for taking part in the Employment Initiative meeting. We hope that you found today's discussions meaningful and valuable to your own work. Before you go, we would appreciate it if you could answer some quick questions about your experiences today as part of our data collection.

Reminder: Completing this survey is voluntary, and if you provided consent, this survey may be used for research purposes. If you do not wish to have this information included in the research study, please check the box below
- o   I do not wish for this information to be included in the research study

1.   What are the top 3 things you learned today?

2.   Was there anything that surprised you? If so, please describe.

3.   Overall, what do you believe are the key factors to help support individuals with FASD through their employment journey?

4. After discussing and learning about the Employment Guide, how might you consider using it in the future? If not, please explain.

5. I feel confident in my abilities to support individuals with FASD through their employment journeys. (scale 1-10)
   - Strongly Agree
   - Agree
   - Neither Agree/Disagree
   - Disagree
   - Strongly Disagree

6. I have the necessary resources and networks to support individuals with FASD through their employment journeys. (scale 1-10)
   - Strongly Agree
   - Agree
   - Neither Agree/Disagree
   - Disagree
   - Strongly Disagree

7. I rate my knowledge of FASD and employment supports and strategies as strong. (scale 1-10)
   - Strongly Agree
   - Agree
   - Neither Agree/Disagree
   - Disagree
   - Strongly Disagree

8. Rate today on a scale of 1 (ineffective) to 10 (effective) in terms of:
   a. The opportunity to network, share resources, and reflect with others invested in seeing individuals with FASD succeed in employment.

   b. How well the discussions increased your knowledge and appreciation of the processes and combined efforts involved in fostering employment success with individuals with FASD.

   c. Overall, how well the meeting was organized and conducted.

Please share any other comments you have below: