



Fetal Alcohol Spectrum Disorder and Employment Report

A current review

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*In Partnership with:
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“The invisibility of the disorder can be a struggle” (Parent of an adult with FASD)

Introduction

This report was prepared by the Canada Fetal Alcohol Spectrum Disorder (FASD) Research Network (CanFASD). The purpose of this report was to identify current employment programs and model frameworks that are currently used to support adults with FASD. The information was collected using two mechanisms: In the first, a literature search was conducted using electronic databases (for published literature) and google search engine (for grey literature). Search terms included “fetal alcohol”; “prenatal alcohol”; “supported employment”; “disabilities”. Additional materials such as reports, handbooks and manuals were also included in the review. Overall there is a paucity of published literature on FASD and Employment. Considerable information was gleaned from resources involving clients with disabilities in general. The first section of this report describes the findings from the literature review.

In the second mechanism, organizations across the country that provide employment support for clients with FASD, were identified, recruited and invited to participate in an interview. A customized questionnaire (Appendix A) was developed to provide insight into the types of approaches and models that are currently employed, as well as the successes and challenges these programs experience. Taken together, the information presented in this report can be used to inform future employment initiatives for clients with FASD.

Fetal Alcohol Spectrum Disorder (FASD)

FASD is the leading known cause of preventable developmental disability among Canadians (1). It is estimated to affect ~ 1% of the population; however, recent studies reveal rates much higher than predicted by long-standing popular estimates (2;3). FASD is a diagnostic term that describes the range of disabilities resulting from prenatal exposure to alcohol (4). The disabilities can be mild to severe, and include physical and mental difficulties that involve cognition, behaviour and emotion. When supported, clients with FASD can lead fulfilling lives and become contributing members of society; however, without support, secondary disabilities such as addiction, mental illness, incarceration and unemployment have all been well documented in the literature (5;6). Importantly, because FASD is a largely invisible disability

(e.g., visually, most clients with FASD appear unaffected), it can compromise the chances for success and can adversely affect quality of life.

Despite the limited literature describing employment in the FASD population, many studies do recognize that individuals with FASD have employment-related challenges (5;7;8). Competitive and fulfilling employment can help develop a positive identity, self-esteem and self-worth. It can be a protective factor against some secondary disabilities associated with FASD, and can reduce poverty and dependency. Cognitive and behavioural difficulties, as well as some socio-economic and preconceived negative expectations associated with FASD make it challenging to join and stay in the workforce (9). These can include difficulties paying attention and/or sitting still for long periods of time; impulsive behaviour, trouble remembering instructions (e.g., not meeting preconceived expectations), tiring easily from having to think and concentrate harder than others and being slow to perform duties. The lack of understanding among employers and co-workers regarding the cognitive and behavioural challenges associated with FASD can also be problematic, placing increased pressure on the individual and creating expectations that are unattainable and/or unfeasible.

A hallmark feature of FASD is impulsivity and for clients with FASD this can further compromise their capacity to find and keep gainful employment. Impulsivity is a behavioural challenge that can manifest as impatience – *“I want a job today, can you help me?”* – and an inability to comprehend the steps and timeline involved in securing successful employment. Employment models that involve significant amounts of paperwork and a slow job placement processes are typically ineffective for clients with FASD. They can lose interest quickly, leading to poor client retention and high turnover rates that preclude successful job placement opportunities.

Although adults with FASD experience vocational challenges both directly (i.e., inherent with their diagnosis) and indirectly (i.e., via their employer) (Table 1), it is important to recognize the many strengths, skills and abilities that clients can contribute to society. For example, some common traits for individuals with FASD include curiosity, creativity, gregariousness, tenacity, friendliness, helpfulness and generosity (10). Many also are very artistic and perform extremely well in environments where routines are well established. Employers that understand the challenges and adapt their processes, interactions and expectations so they are manageable to clients with FASD create a win-win situation solution. This can empower clients to overcome difficulties and retain paid employment that makes them feel valued and boosts self-esteem (9).

Table 1. Challenges and Solutions

Challenges	Solutions
<p>Clients</p> <ul style="list-style-type: none"> • Address safety concerns that clients and their families may have related to working in the community 	<ul style="list-style-type: none"> • Ensure clients can self-advocate when there are problems • Explain safety procedures and policies using language that clients understand • Help clients feel comfortable asking questions when they do not understand an instruction • Teach clients time management tools (e.g., reminders, alarms) to ensure they go to work, arrive on time, can use public transport
<ul style="list-style-type: none"> • Cognitive deficits in communication and information processing 	<ul style="list-style-type: none"> • Avoid using complicated jargon, acronyms and speaking too quickly without pausing, • Recognize coping mechanisms that clients may retain when they are overwhelmed, anxious and frustrated (e.g., pretending to understand, avoiding a task, retreating or quitting) • Use respect, patience, and person-first approaches • Advocate to educate to help clients with FASD secure employment
<p>Employers</p> <ul style="list-style-type: none"> • Employer concerns about workplace training and supports for clients with FASD 	<ul style="list-style-type: none"> • Educate employers to overcome perceived stigma and stereotypes associated with FASD diagnoses • Foster open channels of communication between employers and support organization to identify problems early and prevent job losses for clients.
<ul style="list-style-type: none"> • Employers and as co-workers, need to understand the unique challenges clients with FASD may have 	<ul style="list-style-type: none"> • Teach employers strategies and approaches for supporting clients with FASD to maximize success and productivity • Provide accommodations to increase likelihood of success

Employment Models

As communities move towards adopting more inclusive employment opportunities for individuals with developmental disabilities, *Supported Employment Models* are beginning to replace traditional *Sheltered Models of Employment*.

Sheltered Models of Employment and day programs offer some vocational activities; however, clients are not paid meaningful wages and include segregated work environments that prevent important opportunities for socialization and building relationships with co-workers (11). These programs traditionally “assign” clients to partake based on the existing programs, and not based on client interests and strengths. Adults with disabilities can feel further isolated from contributing to their communities, and they do not have opportunities to learn and practice employment skills or expand their personal skill sets. These clients often report lower levels of self-esteem and job satisfaction compared to clients in supported employment programs (11). In this model, individual career aspirations are not considered and there are few opportunities for clients to meet their vocational goals.

A *Supported Employment Model* focuses on creating a good ‘fit’ between the employee’s abilities and work environment. It involves providing individualized guidance to individuals with disabilities about employment, which departs from traditional employment models that involve lengthy periods of assessment and prevocational training (12). Central to *Supported Employment Models* is the integration of clients with disabilities into the workplace setting. In this model, organizations and agencies provide support to clients that can maximize their chances for success. Clients can receive employment supports such as resume writing, job coaching, role modelling, supervised work experiences and ongoing access to staff who can work with them address and overcome challenges. This enables clients to develop relationships with their co-workers and feel a sense of autonomy as they contribute to the productivity of the business in which they are employed. While Sheltered Models of Employment receive more funding than Supported Employment models, this translates to higher cost to stakeholders and tax payers and precludes clients with disabilities from obtaining meaningful employment opportunities that provide them with a means of financially supporting themselves (at least in part).

In a 2013 Cochrane review, the effectiveness of supported employment compared with other approaches to vocational rehabilitation or treatment as usual, was evaluated in adults with severe mental illness (13). Despite the limited available studies (n=14 randomized controlled trials were included), supported employment was demonstrated as an effective approach to improving the number of vocational outcomes relevant to people with severe mental illness.

Supported employment significantly increased levels of employment during the course of the studies and led to an increase in the length of competitive employment when compared with other vocational approaches. The review concluded that supported employment positively affected the length and time of employment; and that clients on supported employment found jobs faster compared to other approaches.

It is not uncommon for clients with FASD to also have a mental health diagnosis making these findings relevant to this population. However, it is important to recognize that clients with FASD often experience additional challenges (see Table 2) that differ from the developmental disability landscape and that are not often considered when delivering supported or customized employment programs.

Table 2. Additional challenges for clients with FASD

- **Often do not have a stable support environment (e.g., family; spouses, friends)**
 - **Criminal records that makes finding a job more difficult**
 - **Childcare responsibilities**
 - **Unsupported living arrangements**
 - **May be struggling with addiction (e.g., problematic alcohol and/or drug use)**
 - **Involvement with other systems such as CW, Mental Health, probation**
 - **Limited role models who work in traditional fields**
 - **Poor understanding of work ethics/rules**
-

Indicators of Success

Due to the changing landscape of employment for individuals with developmental disabilities, there is a growing emphasis on community involvement and integration. The supported employment model has been shown to positively impact clients with disabilities who work in the community with supports and a general level of satisfaction from these clients has been revealed (14-17). The integrated approach for employment is being adopted in many countries such as Canada and the United States (18). Moving forward, data is needed to demonstrate a quantifiable impact of supported employment for clients with developmental disabilities to inform policy and programs. Standardized performance indicators are needed.

A collection and application of a set of standardized service delivery indicators have been described for twenty-three supported employment programs for clients with developmental disabilities in a paper by Rush and Dale (n.d.) (19). Evaluation data is critical for demonstrating

benefits and supporting these types of programs. Several examples from this paper are outlined in Table 3.

Table 3. Indicators of Success

Service Delivery Indicators

- **Number of service recipients employed in the study period**
- **Job classification**
- **Average hours worked per week**
- **Average hours of support per week.**

Standardized Performance Indicators

- **Number of employment agreements**
 - **Number of closed cases**
 - **Number of people employed**
 - **Job classifications**
 - **Nature of disability**
 - **Hours worked and earnings**
-

As the employment landscape for clients with developmental disabilities changes, it is critically important to consider mechanisms for evaluating success. The indicators outlined in this paper can be used to create an accurate picture of supported employment in a given region by creating an evaluation model and planning tool for organizations. Consolidating regional data can then be used to create benchmarks or standards for service delivery, which in turn can be used by all agencies to compare results and motivate programs, agencies and organizations to meet or surpass these standards. These data form the basis of an evaluation model that can be used to nurture continuous growth and improvement. Performance indicators are important planning tools for governments, communities and individual service providers; and can illustrate the types of staff training and resources required to ensure success. Ultimately, a culture of evaluation and continuous quality improvement within an organization and the larger service delivery network can be created to better meet the complex needs of clients with developmental disabilities such as FASD.

Employment Program Interviews

An external consultant was contracted to identify employment programs for clients with FASD, draft a questionnaire (Appendix A) and invite them to participate in the project. Organizations were identified in three main ways. First, a small list was provided by Audrey McFarlane, Executive Director, Lakeland Centre for FASD. Second, an internet search was conducted using

the words "FASD" and "Employment" in the google search engine. From the search results, the first 3-4 pages were scanned to identify organizations that specifically stated that they served the FASD population in their employment program. Finally, several additional organizations were identified following the completion of an interview, as the last question asked respondents "Do you know anyone else in Canada doing employment programs for people with an FASD?"

A total of thirty programs were identified and invited; nine interviews were conducted (31.0% response rate). Of these organizations, 3 were based in Alberta (33.3%); 3 in British Columbia (33.3%); 1 in the Yukon (11.1%); 1 in Manitoba (11.1%) and 1 participant based in British Columbia, who has extensive experience in program development for clients with FASD also provided an interview (11.1%). One organization was unable to participate in the interview; however, they provided a final report describing a pilot employment project they conducted.

Overview of Participating Organizations

Ability Resource Centre

1610 – 29th Street North

Lethbridge AB

T1H 5L3

Ph: 403-329-3911

<http://www.abilityresource.ca/ability-resource-centre/>

Ability Resource Centre is a place for individuals to build friendships, learn, be productive, explore interests and talents, develop skills and gain confidence. Individuals are supported to be involved in general community social, recreational, educational, arts and culture activities. Ability Resource Centre is a division of the Rehabilitation Society of Southwestern Alberta, a not-for-profit registered charity. It is the largest organization in Lethbridge that supports individuals with disabilities. They have many contracts and serve a very large population. Their services are primarily for adults, but they have recently started providing services for youth via the school system (>15 years of age). In addition, they provide hands-on work experience in a woodworking shop and in two bottle depots in their facility. They can transition students into adult program very smoothly. Many FASD clients gain access to their programs through the school-work experience service or referrals from social workers. Through their work experience in the woodworking shop, clients with FASD can access other work experience in the community. Ability Resource Centre also provides coaching and on the job support.

Prospect Human Services (Head Office)

915 33 Street NE

Calgary, AB

T2A 6T2

Ph: 403.273.2822

Fax: 403.273.0090

Email: info@prospectnow.ca

www.prospectnow.ca

Prospect Human Services is a not-for-profit organization building a productive society by embracing the diversity of its citizens. Prospect builds capacity for inclusivity by collaborating with businesses, individuals and the greater community to develop systems and strategies for greater integration. The organization provides a diverse range of community and employment supports to a variety of client groups, including unemployed and underemployed Albertans, mature (50 years plus) workers, at-risk youth, and people with disabilities. They have a number of different employment programs including a Pan-disability contract that supports 55 individuals with FASD.

Lakeland Centre for FASD

4823 50th Street

PO Box 479

Cold Lake, AB

T9M 1P1

Ph: (877) 594-5454

Fax: (780) 594-9907

www.lcfasd.com

Lakeland Centre for FASD envisions a region with no new FASD births and where currently affected individuals are well supported. Their mission is to establish and ensure that accurate information about FASD, and effective prevention, diagnostic and support services are available in the Lakeland area, including employment services for clients diagnosed with FASD or for clients who are linked to the Lakeland Centre for FASD. They provide both group activities and individualize services around employment, especially for clients with high needs. Additionally, staff provide education to employers in the community about employment services for clients with FASD.

Langley Association for Community Living (Head Office)

23535 - 44th Avenue

Langley, BC, V2Z 2V2

Ph: 604-534-8611

Fax: 604-534-4763

Email: main@langleyacl.com

www.langleyacl.com

Langley Association for Community Living offers supported employment services to individuals with a developmental disability who want to be employed in the community over the last 25 years. Their program includes comprehensive employment service; working in partnership with job seekers, the business community, the Ministry of Social Development, School District and Community Living BC (CLBC). In 2008, they established the employment initiative to develop a strategy aimed at increasing employment opportunities for people with developmental disabilities. The Community Action Employment Plan is intended to look at increasing employment opportunities for people who want paid employment, help with youth transition planning, provide more support for self-employment, and better employment opportunities for people who are under-employed or in programs that aren't work-related. They offer 5 types of services: Traditional Supported Employment (for clients who meet the IQ requirement of <70, and would include clients with FASD); Youth Work; Customized Employment; Personal Support Initiative (often includes clients with Autism and FASD) and Supported Self Employment.

The Asante Centre (Program Offices)

103 - 22356 McIntosh Avenue

Maple Ridge, B.C.

V2X 3C1

Ph: 604-467-7101 Toll Free: 1-866-327-7101

Fax: 604-467-7102

Email: info@asantecentre.org

www.asantecentre.org

The Asante Centre is a not-for-profit organization providing a variety of services related to Fetal Alcohol Spectrum Disorder (FASD), Autism Spectrum Disorder (ASD) and other complex developmental needs. The Centre offers primarily assessment and diagnostic services; however, FASD is a primary focus. It is the only place in BC that has funding for adult assessments. Although they do not have specific employment programs, it is an important component to their assessment to ask questions about employment. Most of their clients are receiving some type of public assistance and they experience challenges securing employment. The Centre is very interested in

creating supportive employment opportunities for clients and has developed a resource for employers to help with supportive employment in their organization. *(Note: interviewee had a specific interest and experience in employment for clients with FASD based on previous work in a Northern community. Responses to the interview questions were based on past experience and current knowledge and expertise).*

Whitecrow Village

P.O. Box 4575 Station A
Nanaimo, British Columbia
V9R 6E8

Email: admin@whitecrowvillage.org

www.whitecrowvillage.org

Whitecrow Village began as a camp for children with an FASD. As it grew, they found that young adults and adults with FASD were the best teachers. The foundation of all *Whitecrow Village* programs is respectful relationship. Other essential elements include: equality and interdependence; routine; structure and consistency; honesty; a focus on strengths; anticipation of success; celebration of unique contributions; intentional, effective, and respectful communication; predictable daily routine; and awareness of tangible and intangible environment. They consistently model appropriate language, actions, attitude, healthy nutrition, and self-care. They insist on maintaining these elements not only prevent problems, but enhance solutions. All rules apply to everybody – volunteers, guests, and youth; there are not many rules, but they are very black and white. The young adults in the camp make a really good team who can support and look after one other. Employment for clients with FASD requires good communication from both sides. When people are well supported they are successful, but supports are removed, it must harder to find success.

Westman Employment Services

#4-217 10th Street
Brandon, MB R7A 4E9
Ph: 204-727-2322
Fax: 204-727-5624

Email: office@westmanemployment.ca

www.westmanemployment.ca

The overall goals of *Westman Employment Services* are: a) To support persons with disabilities in preparing for and retaining employment with an eventual transition to independence in the workplace with natural supports whenever possible; b) To support persons with disabilities to obtain and maintain employment that is suitable to each participant's interests and abilities; and c) To increase the participation in the community through employment. *Westman*

Employment Services started in April 2013, but has a long history in the province of Manitoba. The province of Manitoba defines “Supported Employment” as 15 hours a week, at least minimum wage, for 12 weeks or more. They are trying to become more community focused and they work with many of clients who are suspected of having FASD. In general they support clients with any disability; currently no one with FASD at this time, but have supported clients with FASD in the past experience.

Yukon Association for Community Living

4230 4 Ave #7

Whitehorse, YT

Y1A 1K1

Ph: 867-667-4606

Fax: 8676674606

E-mail: yaclwhse@northwestel.net

www.ycommunityliving.com

Yukon Association for Community Living provides advocacy, public awareness and education, and a variety of programs that broadly support the inclusion of people with disabilities. For the general public and other agencies, they act as a resource hub providing referrals and access to a comprehensive resource library. They also deliver specific programming such as workshops and conferences on various disability issues, public education on guardianship, and a variety of social programs. They recently added employment services including job coaching, employer matching, and a youth transition-to-work program. Currently, they are running a national program called “Ready, willing and able” for clients with developmental disabilities, including FASD. FASD is the one of the most common disabilities they see.

Northwest Regional Fetal Alcohol Spectrum Disorder Society Mackenzie Network*

Box 3668

High Level, AB

T0H 1Z0

Ph: (780) 926-3375

Email: wanda.fasdsociety@telus.net

www.nwr-fasd.ab.ca

Northwest Regional Fetal Alcohol Spectrum Disorder Society Mackenzie Network endeavours to enable communities to work towards FASD free births, while supporting those born with FASD and their vision is working together towards a future free of FASD. The goals of their program are: To coordinate with the Health Region to provide services within the region; To increase awareness, knowledge and resources for families and individuals with FASD across the lifespan;

To collaborate with and support schools, communities and agencies with the resource to support children and families living with FASD; To remove the stigma and break down barriers surrounding FASD; and To have no more births with Fetal Alcohol Spectrum Disorder. In 2015 they conducted a pilot employment program for clients with FASD called the “Employment Coach Program”. This program was created to support individuals with FASD to access and maintain part-time employment through support from an employment coach. The employment coach would also support employers and co-workers in understanding how to best support an employee with FASD.

****Provided a report a pilot project, but were unable to participate in the interview. Report findings are summarized, but not included in the collated interview results.***

Interview Results by Question

1. How long did it take to get your program up and running?

Four of the organizations responded that it took 6 months – to a year to establish the program, complete the administrative tasks (e.g., by laws, board structure, job descriptions/titles etc.), obtain sufficient funding and begin supporting clients. One organization reported a 3 year timeline to get everything into place largely due to funding challenges and lack of support from potential employers. Four did not respond or the question was not applicable (e.g., program was already established when they started working).

2. How many staff do you have for this program?

The number of staff per program varied based on the organization. Most (5 organizations) had between 2-20 staff, though it was not clear if they were all paid employees. One organization (Whitecrow Village) had no paid staff, and was run entirely by volunteers due to instability in funding. Two organizations responded that various staff members were involved at different points in the process depending on the needs and capabilities of the client. One interviewee did not respond.

3. What is the purpose/goal of your program?

All of the organizations shared many similarities in their response to the purpose and goal of their program. Many indicated their organization help clients find “rewarding” and “meaningful” work opportunities – be them paid or volunteer. Providing clients with a sense of “value”; “productivity”; “community” and an opportunity to become contributing members of society and good citizens were common themes reported by most

respondents. As well, these programs were also aimed at removing employment barriers through good communication, awareness, and education, and to evaluate the benefits of the supported employment model.

4. How do clients access your program? (self-referral? Is a diagnosis of FASD needed?)

A few respondents (n=3) indicated that self-referrals were acceptable and in the case of the Yukon Community Living, self-referrals comprised the major route for accessing employment support. Many organizations maintained strong connections and relationships with existing FASD-specific organizations, network or agencies; from which clients may be referred or programs operated within a larger FASD diagnostic and assessment capacity. Schools, Children's Aid Society, Government agencies, community and professional groups, or families were also reported sources for referrals. In one case, clients needed only to register for programs online. Interestingly, only of the described programs reported a formal FASD diagnosis as a requirement to accessing services; for all others suspected or documented neurodevelopmental challenges were sufficient for accessing program support.

5. How long does the program last or how long do you support the client?

Most organizations (n=8) reported that the timeline was based largely on the needs of the client and the extent of support they needed; some clients required a short term of support, others required longer and there were also clients who would always need some level of support or interdependence. In 3 cases, funding emerged as a contributing factor to the length of time resources were available; especially in the case where all staff were volunteers. For organizations that had a set timeline in their model, the commitment varied between 6 weeks to 2 years, though if a client's files was "closed" and they returned for support, no one was denied (as long as resources were still available).

6. What is your programs capacity? How many clients can you support at one time? (Per month/year?)

Across many organizations, respondents reported a fluid process for client support and capacity that was largely based on needs and sustainable funding. Reported capacity varied from 35 -121 clients; however, not all of those cases represented clients with FASD. In most organizations, support was provided for any individual with a developmental disability (which would include FASD). One organization did not respond and another had no current capacity due to lack of funding. Staffing requirements (group activities where 1 staff could work with several clients versus 1-on-1 support) also influenced the number of clients that could be supported at any given time. Two organizations reported an annual referral rate of 14 new clients per year and 10-20 new clients per year.

7. *What is the demographic of your clientele? (Age/gender/citizenship status/etc.)*

Several organizations (n=4) reported a shifting trend towards younger clients seeking supported employment resources, especially as they graduated from high school. Most reported a relatively even split between male and female clients; however, two organizations reported more women clients than men (Lakeland and Yukon). Three interviewees reported providing services to First Nation clients – varying from 25% to predominantly the entire case load (Yukon). Interestingly, one organization (Ability) indicated that *“those with an FASD are the ones falling through the cracks, especially with PDD [Persons with Developmental Disabilities] funding as they don’t meet the IQ criteria for funding but still need supports”*. Clients with FASD can have a wide range of IQ scores that can be misleading and not always reflective of their level of competence with respect to obtaining and keeping meaningful employment.

8. *Can you describe how your program works?*

All of the organizations who responded to the question (n=7) described a strength-based model, where individuals worked with staff to identify interests, skills and strengths designed to meet the clients goals. Most of the programs provided specific hard and soft skills training that included strength finding; resume building; job searching; interview preparation; career and transition planning; and employment coaching. One program (Yukon) specifically reported employer engagement as a major component to the success of their services and subsequent on-site job support. The Lakeland program also offered supervised, supported-employment opportunities for clients within their organization.

9. *How do you measure success? What indicators do you use?*

Based on the responses provided, the various measurement tools and indicators for success often varied on the type of program and the funding body. Several programs opted to measure success by client engagement (e.g., participating in programs; gaining employable skill sets), while other organizations measured success based on whether clients maintained employment over the course of the program (e.g., retention times, 30, 60, 90 days...etc.). For the Westman program, meeting the provincial criteria for supported employment (15 hours/week, minimum wage or better; at least 12 weeks of employment) was a measure of success. Funders had set measurement criteria that programs had to adopt, even if the data were not always reflective of how staff would quantify success. For example, in one organization (Yukon), they were required to provide number of hours worked (either less or greater than 15 hours/week). However, finding employment and maintaining employment would have been a better indicator. One comment that was of interest as novel success measure was the interaction with employers. For example, if a previous employer returned

to the program to hire new employees, then this could be an indication of a successful program.

10. What models/frameworks do you use in programming?

Many organizations reported using some form of the Supported Employment model or best practices. These models were often adapted to meet the needs of their clientele and within the resources of their organization. Some interviewees reported receiving specific training that helped to inform the development of their program such as positive behaviour support plans and case consultations. Importantly, one respondent expressed “...that you have to manage the environment, not the individual.....[you need a] Brain based disability lens.” This model adopts the client-focused, strength-based approach where one identifies the individual first and not their disability. One organization also mentioned using the “Mentorship Model”, in which a client with a disability is partnered with a more experienced colleague who help support, troubleshoot and educate to maximize the likelihood of success.

11. What strategies do you find are the most effective?

Organizations reported common themes regarding effective strategies for implementing their programs. These typically included: “Strength-based/Interest-based” approaches for clients (e.g., know your clients interests and strengths); “Relationship Building” (e.g., good communication with employer and good matching with clients); and “Time Management” (e.g., teaching how to set alarms; reminders; transportation). One respondent indicated that it is important to teach clients “self-advocacy” skills to ensure they are comfortable stating when they do not understand something. Several staff expressed the need to be “flexible” and “creative” to support their clients. For example, “being creative and flexible, helping the find strategies to self-regulate” and “Always thinking outside the box” were two responses. One interviewee described a process they had adopted when communicating with potential employers: the value proposition. In this approach, employers were told 3 values about hiring an individual with disabilities before they were asked to participate: “Why would the employer want to hire?”, “How they will save time” and “How they will increase productivity”. In this way, employers recognized what the organization would do for them and how they could benefit.

12. What strategies do you find are the least effective?

Responses were consistent across all organizations. The predominant theme was the philosophical shift from “any job is a good job” (e.g., making clients change to meet the job requirements) to an emphasis on finding “the right fit between the employee and employer” based on the interests and strengths of the client. One organization indicated

that workbook/paperwork approaches were very difficult for this clientele. Assuming job readiness and prescriptive models for employment were also reportedly ineffective; approaches needed to be individualized and tailored. “On the go” employment training (e.g., Work Experience Model) was also reportedly; pre-employment support and individualization were requirements for successful employment. Staff need to have sufficient time to work with their client, being “rushed” or “in hurry” was also ineffective.

“Supported Employment is a team sport. There are many players that support – family, coach etc. – whatever support you can get. The more support you can get, the better.” (Langley)

13. What are the main challenges that you face?

Several organizations indicated that maintaining client engagement and retention can be challenging: “FASD population have a hard time prioritizing” and may not want to go to work or do not understand the consequences of their actions (e.g., getting fired for missing work to hang out with friends). Work ethic can change on a daily basis jeopardizing job security and leading to difficulties supporting the client due to their fluctuating needs. Instability in the home life can also be a challenge; one organization reported that they provide employment services only and are not always aware of the other challenges facing their clients (e.g., housing, mental health etc.). Employer support and understanding were also reported challenges in terms of “stigma” and “stereotypes” associated with a FASD diagnosis. Other organizations reported that the current economy was not receptive to “supported employment” and that funding was an ongoing concern.

14. What is your funding model? How exactly are services funded? Grant money or sustainable funding?

Most organizations received some form of governmental support for their employment program. In several cases, additional grants supplemented this funding, and for others grants and contracts comprised the predominant source of funding. Two organizations indicated some fundraising resources and one included fee-for-service to reconcile some costs associated with their program.

15. Do you know anyone else in Canada doing employment programs for people with an FASD?

Some organizations suggested other employment programs. Attempts were then made to contact these additional programs and invite them to complete the interview questionnaire.

Employment Coach Pilot Program (Northwest Regional Fetal Alcohol Spectrum Disorder Society Mackenzie Network)

The Employment Coach program was created to support five individuals with FASD to access and maintain part time employment through support from an employment coach during the length of the project. The employment coach also provided support to employers and co-workers in understanding how best to support someone impacted with FASD. Overall the initiative helped the individuals realize that they do have skills, some basic training and the opportunity to be employed with support. It also provided the opportunity for the individuals to begin the process of planning for future employment.

Several comments from the project were relevant to this report. During the pilot, staff found that it took significantly longer than anticipated to set up the project and that a number of factors such as the economy and needs of the client (e.g., childcare, identification, etc.) often took precedent over the needs of the program. Of note, a downturn in the economy may also have hindered the success of the program as fewer jobs in general were available during the time period of the project.

Many clients had never been employed, and additional time and resources were devoted to completing these unforeseen administrative tasks such as obtaining necessary identification and social insurance numbers, which had not been originally accounted for in the project timeline. The need and time to develop a relationship with the Employment Coach and the individual had also not been anticipated in the timeline. Once the relationships were established, the individuals were much more willing and available to take the steps to prepare and take on employment. Overall the project did provide 8 of the 11 individuals' employment experience during the period of the program.

Summary of Findings

While the initial response of 9 interviews was considered disappointing, on further evaluation and review of the responses, it was clear that the proportion of participants were representative of the current Supported Employment approach as there was significant overlap in the information collected. Interestingly, many organizations have adopted a similar approach to supporting clients with FASD and recognize the need for individualized and customized approaches to maximum success. Many common themes emerged pertaining to the most and least effective strategies for the FASD population.

Key Findings

- **Strength-based approach (person-centred) was most effective, but also resource-intensive in terms of staff time and flexibility**
- **Secure funding streams were a constant challenge and in some cases prohibited programs from running**
- **Relationship building both between staff and clients; and also between employer and organizations were critical. Education, awareness and support were significant contributors to the overall success of the employment opportunity (organizations need to educate perspective employers about FASD and work collaboratively to support these clients.)**

From the limited available literature and data collected from the interviews, it is apparent that Supported Employment is a suitable model for clients with FASD who are seeking employment. It was extremely encouraging to discover that programs do exist to support adults with FASD in their search for employment; and that these programs are tailored to their needs. The Supported Employment model enables clients to experience and explore employment opportunities that would not otherwise be available to them. While the upfront costs may seem high, the long term benefits are significant. Moving forward, as communities become more integrated and inclusive regarding clients with developmental disabilities, it is critical to recognize what models are currently successful and capitalize on these opportunities to make further improvements in their delivery and sustainability.

Reference List

- (1) Public Health Agency of Canada. Fetal Alcohol Spectrum Disorder (FASD). 2014. (<http://www.phac-aspc.gc.ca/hp-ps/dca-dea/prog-ini/fasd-etcaf/index-eng.php>).
- (2) May PA, Baete A, Russo J, Elliott AJ, Blankenship J, Kalberg WO, et al. Prevalence and characteristics of fetal alcohol spectrum disorders. *Pediatrics* 2014 Nov;134(5):855-66.
- (3) May PA, Keaster C, Bozeman R, Goodover J, Blankenship J, Kalberg WO, et al. Prevalence and characteristics of fetal alcohol syndrome and partial fetal alcohol syndrome in a Rocky Mountain Region City. *Drug Alcohol Depend* 2015 Oct 1;155:118-27.
- (4) Cook JL, Green CR, Lilley CM, Anderson SM, Baldwin ME, Chudley AE, et al. Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan. *CMAJ* 2016 Feb 16;188(3):191-7.
- (5) Streissguth AP, Bookstein FL, Barr HM, Sampson PD, O'Malley K, Young JK. Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *J Dev Behav Pediatr* 2004 Aug;25(4):228-38.
- (6) Pei J, Denys K, Hughes J, Rasmussen C. Mental health issues in fetal alcohol spectrum disorder. *J Ment Health* 2011 Oct;20(5):438-48.
- (7) Streissguth AP, Barr HM, Kogan J, Bookstein FL. Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE). Final report to the Centers for Disease Control and Prevention. University of Washington, Fetal Alcohol and Drug Unit: Seattle; 1996. Report No.: Tech. Rep. No. 96-06. ()).
- (8) Baldwin MR. Fetal alcohol spectrum disorders and suicidality in a healthcare setting. *Int J Circumpolar Health* 2007;66 Suppl 1:54-60.
- (9) Salmon JV, Buetow SA. An exploration of the experiences and perspectives of New Zealanders with fetal alcohol spectrum disorder. *J Popul Ther Clin Pharmacol* 2012;19(1):e41-e50.
- (10) Community Living British Columbia. Supporting success for adults with fetal alcohol spectrum disorder (FASD). 2011. (<http://www.communitylivingbc.ca/wp-content/uploads/Supporting-Success-for-Adults-with-FASD.pdf>).
- (11) Hale R, Stainton T, Tomlinson J, Center for Inclusion and Citizenship. Social and economic outcomes: Are supported employment services for individuals with developmental disabilities a good investment? (<http://www.communitylivingbc.ca/wp-content/uploads/Employment-Is-it-a-Good-Investment-lit-review.pdf>).

- (12) Moll S, Huff J, Detwiler L. Supported employment: evidence for a best practice model in psychosocial rehabilitation. *Can J Occup Ther* 2003 Dec;70(5):298-310.
- (13) Kinoshita Y, Furukawa TA, Kinoshita K, Honyashiki M, Omori IM, Marshall M, et al. Supported employment for adults with severe mental illness. *Cochrane Database Syst Rev* 2013;9:CD008297.
- (14) Mank D, Cioffi A, Yovanoff P. Analysis of the typicalness of supported employment jobs, natural supports, and wage and integration outcomes. *Ment Retard* 1997 Jun;35(3):185-97.
- (15) Pedlar A, Lord J, Van Loon M. Supported employment and quality of life. *Canadian Journal of Community Mental Health* 1990;9(2):52-61.
- (16) Ochake J, Lord J, Roth D. Workplaces that work: Successful employment for people with disabilities. *Journal of Developmental Disabilities* 1994;3(1):29-50.
- (17) Test DW, Hinson KB, Solow J, Keul P. Job satisfaction of persons with supported employment. *Education and Training in Mental Retardation* 1993;28(1):38-46.
- (18) Kiernan WE, Butterworth J, McGaughey M. Trends and milestones. *Ment Retard* 1995 Feb;33(1):64.
- (19) Rush B, Dale JM. Regional application of standardized performance indicators for supported employment programs. (<http://citeseerx.ist.psu.edu/viewdoc/download;jsessionid=F5047060D738A66791E612EC195EBE66?doi=10.1.1.490.7867&rep=rep1&type=pdf>).

Appendix A: Program Interview Questions

1. How long did it take to get your program up and running?
2. How many staff do you have for this program?
3. What is the purpose/goal of your program?
4. How do clients access your program? (self-referral? Is a diagnosis of FASD needed?)
5. How long does the program last or how long do you support the client?
6. What is your programs capacity? How many clients can you support at one time? (Per month/year?)
7. What is the demographic of your clientele? (Age/gender/citizenship status/etc.)
8. Can you describe how your program works?
9. How do you measure success? What indicators do you use?
10. What models/frameworks do you use in programming?
11. What strategies do you find are the most effective?
12. What strategies do you find are the least effective?
13. What are the main challenges that you face?
14. What is your funding model? How exactly are services funded? Grant money or sustainable funding?
15. Do you know anyone else in Canada doing employment programs for people with an FASD?