

Best & Emerging Practices for Individuals and Families affected by FASD throughout the Lifespan

Final Report

Calgary Fetal Alcohol Network

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Introduction

The Calgary Fetal Alcohol Network (CFAN) is a collaborative network of professionals, organizations, and individuals aimed at improving quality of life for those affected by FASD. CFAN is a steward of provincial funding in FASD assessment and diagnosis, targeted prevention, and supportive services. Our stakeholders work together to share information, reduce duplication, and to promote collective action for the FASD community. We believe that with the right supports, individuals and families affected by FASD can lead positive, meaningful lives.

CFAN members (i.e., funded agencies and other FASD service providers in Calgary and area) provide a variety of support services to individuals and families impacted by FASD. Provincial evaluation data and CFAN community-based assessments suggest that these services are impactful, yet vary considerably by such factors as target audience, program design, and measurable outcome. CFAN currently has limited evidence to support these services over other models and as such, there remains a critical need to better understand established and emerging best practice in FASD intervention across the lifespan, and to use this evidence-base to inform service delivery and evaluation among both FASD-specific service providers and other community-based service providers that offer supports to clients with FASD (e.g., community and family resource centres, friendship centres, community development programs).

Thus, CFAN has undertaken the *Best and Emerging Practices for FASD* project, which aims to inform the practice of CFAN and its funded agencies through an examination of the best practices for FASD intervention and support through the lifespan, with a particular focus on areas where CFAN is most active within the community.

The project will increase CFAN's capacity as an organization and a network to promote best or promising practice interventions and to utilize this knowledge within our planning, service delivery, and evaluation. It will enable CFAN to provide service providers with practical tools to increase the effectiveness of their programs. The project will also increase CFAN's engagement with those it serves, including relevant stakeholders within its funded agencies, the FASD community, and the community of social service providers in Calgary and area.

The following report is based on evidence collected from the academic and non-published (i.e., grey) literature, qualitative interviews with stakeholders in the community, and a survey to caregivers and service providers in the Calgary region. This information will be used to inform CFAN's practices and to educate the community as the project evolves.

Methodology

This project took a mixed methods approach to examining the evidence around supporting individuals and families affected by FASD throughout the lifespan.

An Advisory Panel was convened for the project and involved members from FASD service organizations, the disability sector, the academic sector, and the CFAN Board. The Advisory Panel met monthly in February to discuss the best way to proceed with the project and to meet its objectives, and then monthly to discuss the progress of the project. The Panel was instrumental in the survey design and in fanning the survey out to their networks across Calgary and the province.

The specific members were:

- Annie-Brae Dixon, WrAP Program, Foothills School Division
- Heather Hayes, Supervisor, Enviro FASD Programming
- Jody Jordan, FASD Parent Mentor, MAPS Program at Woods Homes
- Candace Goheen, Employment Coordinator, The Worx Program, Prospect Human Services
- Jim Des Roches, Manager, Workforce Councils, Alberta Council of Disability Services
- Danna Ormstrup, Executive Director, Foothills Fetal Alcohol
- Allyson Dann, FASD Parent Advocate, Parent Support Association
- Dr. Katrina Milaney, Assistant Professor, Community Health Sciences, University of Calgary
- Meaghan Bell, CFAN Board Member
- Cathy Lane Goodfellow, CFAN Board Member

The Advisory Panel determined that the following methods would help to reach the project's objectives:

- 1) A literature review to gather the available academic and grey literature on best or promising practices for interventions for individuals with FASD and their families throughout the lifespan. The focus of the review was on FASD-specific literature, however in some areas, research in other areas was utilized to fill in gaps (e.g., pan-disability research).
- 2) A community consultation in the form of focus groups was conducted to gather information and expertise on existing practices in CFAN's funded programs and the programs of other stakeholders within Calgary. A total of five focus groups were conducted with professionals from the FASD sector, caregivers of individuals with FASD, and stakeholders from the disability sector.
- 3) A community survey was conducted to assess the community knowledge of FASD, FASD-informed practice, and services within the Calgary region. The survey was available in two forms: one for professionals who may work with individuals with FASD and one for caregivers whose families were affected by FASD.
- 4) Assessment of the evidence to determine the level of evidence for each piece of information. This scale was based on that used by the Province of Alberta in their *Best Practices for FASD Service Delivery* Report and used in Health Canada's (2000) report titled *Best Practices: Fetal Alcohol Syndrome/Fetal Alcohol Effects and the Effects of other Substance Use during Pregnancy*.
 - a. **Good Evidence** = 2 or more controlled studies
 - b. **Moderate Evidence** = 2 or more quasi-experimental studies or 1 controlled study
 - c. **Some Evidence** = 2 or more case studies or evaluations without control/comparison groups, or 1 quasi-experimental study (i.e., non-random comparison group)
 - d. **Expert Consensus** = Evidence that has not been formally researched or evaluated, including the perspectives of consumers, expert practitioners, educators, community or agency reports, etc.

- 5) A revision of the CFAN Logic Model and evaluation strategy will be conducted, using the available evidence to ensure that program evaluations are based on best/emerging practice.
- 6) Knowledge translation will occur with CFAN's funded agencies, caregiver groups, targeted stakeholders within the Calgary region and the community. Knowledge translation may include community presentations, infographics, a report, and/or webinars.

Items 1 through 4 have been completed and the Project Advisory Panel and the Project Coordinator are moving on to items 5 and 6. These should be completed by December 2015, with knowledge translation continuing to evolve and grow over time.

Survey Results

Two surveys were conducted as a part of this project: one for professionals who may work with individuals/families affected by FASD in their practice; and one for caregivers whose families are affected by FASD. Over 200 responses were obtained using the website 'SurveyMonkey' – 162 for the professional survey and 45 for the caregiver survey. The results are discussed below.

Professional Survey

There were 162 responses to the survey. Most of the respondents worked within the urban Calgary region (88.4%). Twenty percent worked in the rural Calgary region, 12.4% worked in a First Nations community in the Calgary area, and 9.3% of respondents worked outside of the Calgary region. The overwhelming majority worked in frontline service provision (64.6%) or management (20%). Approximately 42.2% of respondents worked with children up to 18 years, 17.2% worked with youth (age 18-24 years) and 40.6% worked with adults (18 years of age or older).

All of the respondents indicated that they had heard of Fetal Alcohol Spectrum Disorder (FASD) and that they knew what FASD was. When asked to give a definition of FASD, the majority of the respondents (n=145) described a disability caused by prenatal alcohol exposure that affects

each individual differently and can impact cognitive and executive functioning, memory, and verbal skills. However, there were a few responses that demonstrated misinformation, such as indicating that FASD can be caused by a father's drinking. These responses, as well as the number of individual respondents who skipped the question, may indicate that more awareness work needs to be done around FASD and prevention.

Most respondents said that they 'sometimes' worked with individuals or families with FASD (58.8%; n=87), as compared with 29% (n=43) of respondents who said they always worked with individuals or families affected by FASD and 11.5% (n=17) who said they rarely or never worked with that population.

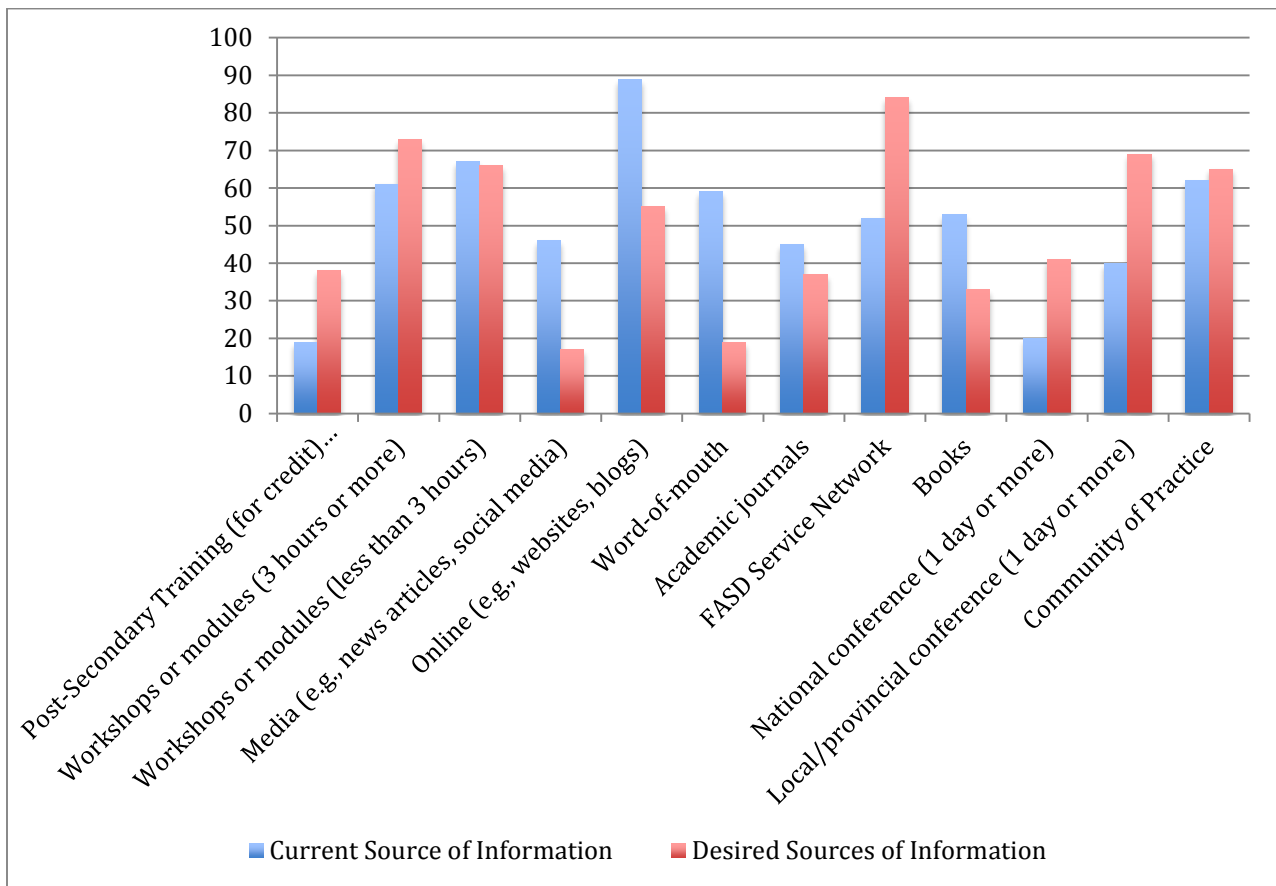
Most respondents indicated that they changed their practice when working with an individual or family affected by FASD (86% said yes and 14% said no). Respondents were asked about how they changed their practice to accommodate for the needs of an individual or family affected by FASD. Their responses included:

- Using simplified and more concrete language
- Being aware of sensory stimulation
- Setting realistic expectation
- Using time management and memory strategies
- Breaking larger tasks down into smaller steps
- Repetition
- Consistency
- Ensuring understanding (e.g., having the individual repeat the information back, watching for 'parroting')
- Using written and visual cues
- One-on-one support
- Structure
- Expecting impulsiveness
- Providing connection to community resources and building natural supports
- Using the diagnostic assessment to guide support

- Taking an individualized approach
- Advocacy and education
- Patience

Respondents were asked what their current sources of information about FASD were as compared with their ideal sources of information. This information is available in Figure 1. It indicates that respondents were going to a variety of sources to get information, however they were currently relying on less reliable information sources (e.g., the media, online, word-of-mouth) when they would prefer to access the FASD Service Network, formalized training, workshops, and/or conferences.

Figure 1: Current and Desired Sources of Information about FASD for Professionals



They indicated that the information they were able to access was helpful, but that more information and resources were necessary because of the need for individualized strategies, evolving and new information always coming available, and they would like more ‘expert’

information. The participants also indicated that it would be helpful if this information was used by other service organizations.

Respondents were also asked about what they considered to be effective practices for serving individuals and families affected by FASD. For the most part, their responses aligned with the strategies that they were using to accommodate the needs for clients with FASD and their families. However, there were several additional strategies, outlined below:

- Listening to the individual
- Working with families (to support the individual and to support the families)
- Using a wrap-around approach
- Using a strengths-based approach
- Understanding how a person's disability impacts them and their family on a day-to-day basis
- Using demonstrations for learning
- Ensuring appropriate environmental adaptation (e.g., classroom set-up, putting away others' possessions)
- Creating and enabling cultural/spiritual connections
- Ensuring respite is available
- Working at a slower pace to allow time for processing
- Trauma-informed care

These results give insight into the types of supports that are being provided in Calgary by professionals at FASD-specific and other service organizations.

Caregiver Survey

There were 45 respondents to the Caregiver Survey. The majority of the respondents described themselves as adoptive parents (60%), with 11% indicating they were foster parents, 20% were legal guardians, 26.7% were kinship/family members, and 2.2% (n=1) indicated they were a biological parent.

Caregivers were asked about the age of the individuals for whom they acted as a caregiver:

- 11.1% said they were caring for a child aged 0 to 6 years
- 42.2% said they were caring for a child aged 7 to 12 years
- 28.9% said they were caring for a youth aged 13 to 17 years
- 15.6% said they were caring for an individual aged 18 to 24 years
- 20% said they were caring for an individual who was older than 24 years

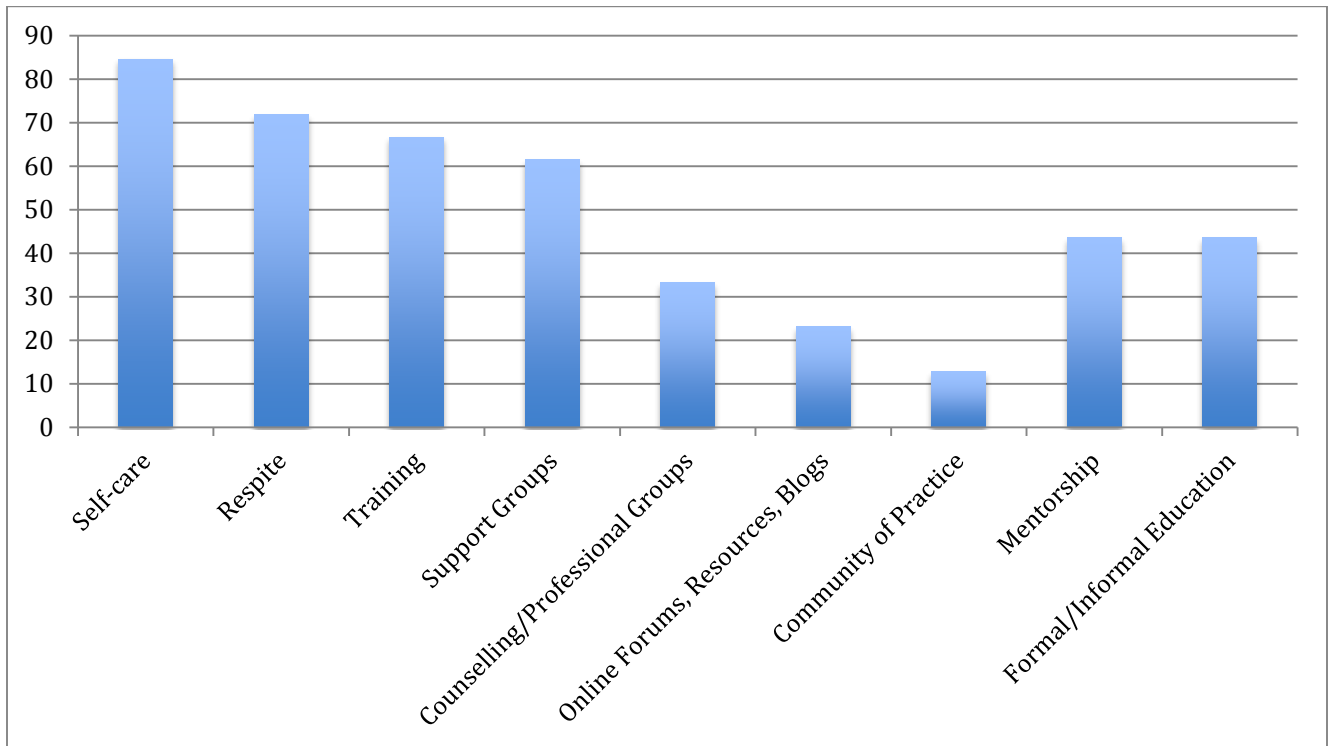
The vast majority (84.2%) of respondents indicated that they lived in the urban Calgary area as compared with 13.2% in the rural Calgary region and 10.5% outside of the Calgary region.

Respondents indicated very similar strategies for providing care for an individual with FASD as those in the professional survey. However, there were some strategies specific to caregiving, which included:

- Financial management
- Working with the individual at their cognitive/developmental age rather than biological/chronological age
- Staying calm and patient
- Education for self and family
- Proactive supports and planning
- Respite
- Recognizing and accepting the individual's disability

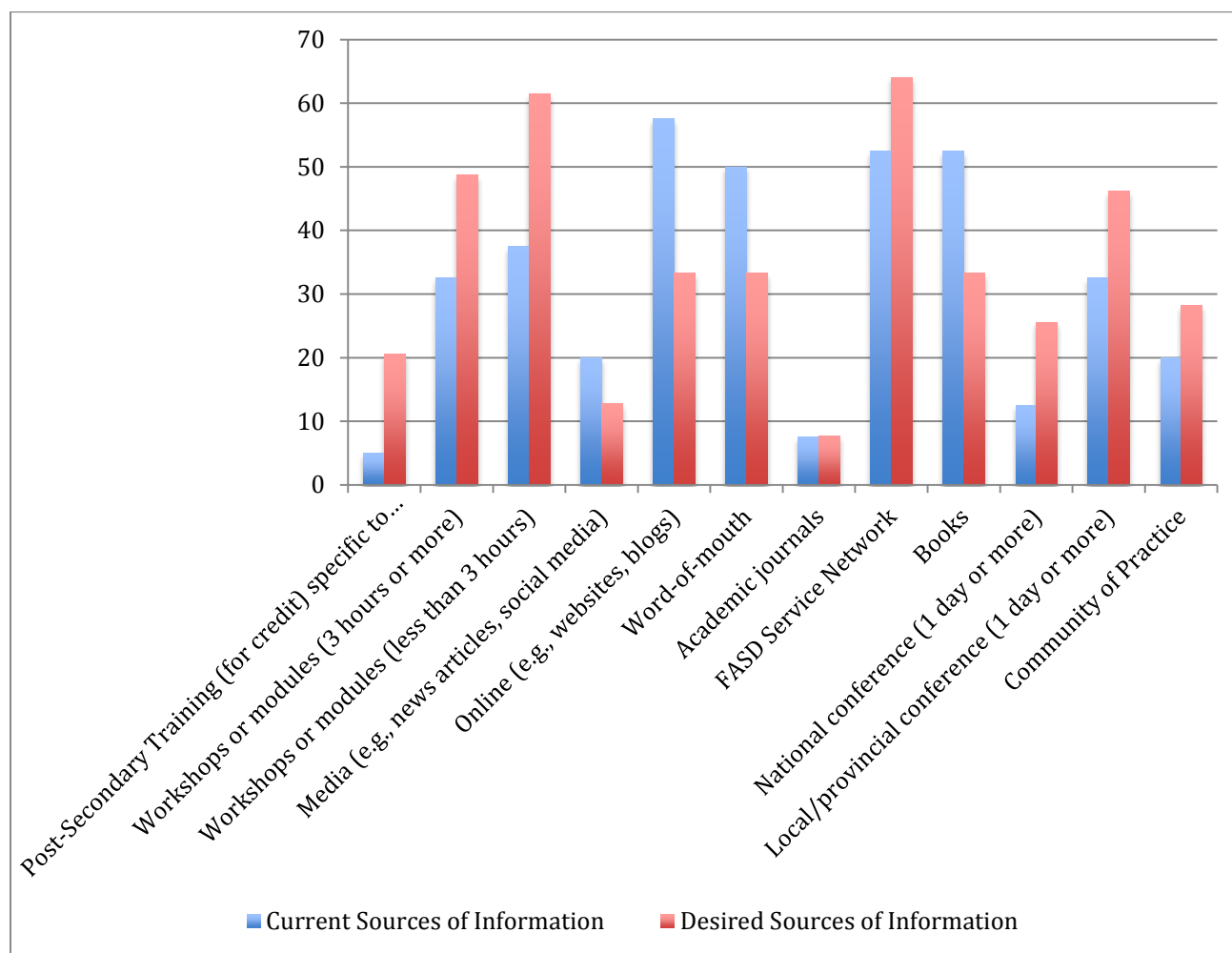
Respondents were also asked about what is useful as a support for them in their role as a caregiver for an individual with FASD. These are outlined in the Figure 2.

Figure 2: Sources of Support for Caregivers



Respondents were also asked what their current sources of information about FASD were as compared with their ideal sources of information. This information is available in Figure 3.

Figure 3: Current and Desired Sources of Information about FASD for Caregivers



Similar to the results of the professional survey, caregiver respondents were currently accessing less reliable sources of information (online, word-of-mouth) but were looking for more training and more reliable information through post-secondary training, workshops/modules, conferences, and support from the FASD Service Network.

Respondents were asked about the supports that they were currently accessing or had accessed. Responses included:

- Governmental services:** Alberta Human Services, Child & Family Protection Services, Calgary Police Service

- **Healthcare:** Alberta Children’s Hospital, psychologists, psychiatrists, family physicians, Alberta Health Services, Foothills Hospital Youth Addiction Program, Sunrise Native Addictions Centre, LaserHealth Solutions
- **Diagnosis:** Medigene
- **FASD-Specific Service Agencies:** Enviros, Foothills Fetal Alcohol Society, MAPS, McMan Services, Woods Homes, Calgary John Howard Society, Prospect Human Services
- **FASD Networks:** Central Alberta FASD Network, Calgary Fetal Alcohol Network
- **Community Organizations:** Ghost River Rediscovery, Avenue 15, Four Directions, Renfrew Children’s Services, Hull Family Services, Closer to Home Services, Between Friends Camp, Kids Hotel, Theraplay, Compass, Access, Mawahi Ataskowin, Calgary Quest School, Office of the Children’s Advocate, Inclusion Alberta
- **Caregiving Supports:** Post-Adoption Supports, Parent Support Group, Supports for Permanency (SFP), Mentorship
- **Funding:** Family Support for Children with Disabilities (FSCD), Disability, Adoption stipend for special needs adoption, AISH, rent subsidies
- **Respite**
- **Training**
- **Online support groups**
- **Natural supports**
- **Educational supports:** Success Coach, Fast Forward Reading Program, Sylvan Learning, Education Wise, Renfrew Educational Services

Respondents were asked what worked or did not work with these supports. Most of the respondents said that the services were working for them, but that **respite** was still a big issue in being able to get support for themselves as caregivers. Respondents identified several other gaps for services in the Calgary region, including:

- Available information and access to information (e.g., no centralized hub, difficult to find current information)
- Navigating the system to get supports after being diagnosed

- Limited services for adults and for youth transitioning to adulthood
- Limited understanding in other professionals (e.g., social workers, teachers, doctors)
- Need for housing and life skills interventions
- Need for financial support
- Limited 'pro-active' supports, rather the focus is on 'crisis-based' supports

Literature Review

A literature review was conducted between February 2015 and June 2015 to examine the state of the literature regarding interventions for individuals and families affected by FASD. The literature review aimed to be as comprehensive as possible; however, it is likely that certain literature (especially grey literature) was unintentionally overlooked. This literature review will form the 'living' piece of the document and will be added to as new information is found or becomes available.

Individualized Support

Individualized support covers the improvement of behavior, executive functioning, and other primary and secondary conditions as it relates to the individuals' everyday life. Because of individualized nature of FASD and the spectrum of challenges that an individual may experience, there is a need to provide supports for the individual, not the disability. Although FASD is a cognitive disability, its impact differs among individuals; functioning in one area may be impaired while others are intact. Furthermore, impairments may impact the individual differently within the day or week (Medalia & Ravheim, 2002). Cognitive impacts may also be affected by environmental stressors, fatigue, distractions, and the effectiveness and availability of supports (Community Living British Columbia, 2011). Thus, it is important to remember the individual and their needs, challenges, and strengths, when providing support and services.

Moderate Evidence

There was moderate evidence to support several models including:

- Attention Process Training, where children with FASD (age 6-12 years) showed significant improvement in measures of sustained attention and non-verbal reasoning (Vernescu, 2007);
- Rehearsal Training, where children with FASD were given a strategy to remember numbers in a digit span task and scored better than the control group at follow-up (Loomes et al., 2008);
- The PATHS curriculum, which is focused on increased emotional development, self-regulation, and social problem-solving, was evaluated using a treatment versus control group. The treatment group (children with FASD) showed a decreased rate of growth in teacher-reported internalizing and externalizing behaviors as well as a sustained decrease in depressive symptoms (Kam et al., 2004).

There was also evidence to show the need for awareness and support for sensory processing disorders in children with FASD to help reframe challenging behaviors and poor functional skills and to better understand the child (Jirikowic, Olson, & Kartin, 2008).

Some Evidence

Several promising practices emerged from literature with 'some level of evidence':

- Early interventions improve developmental outlook (Bertrand, 2009; Streissguth et al., 1996)
- Using a client-centered model of support that promotes the natural strengths and resources of individuals and their families is ideal for building on an individual's strengths, improving their functioning, and minimizing secondary conditions (Hall, Cunningham, & Jones, 2010).
- Using computer-based interventions may support learning in children with FASD. A study of 32 children with FASD, aged 4 to 10 years showed significant gains and generalization of knowledge and skills in a real-world situation after participating in a computer-based intervention to improve fire- and street-safety skills. The authors noted that the intervention was presented in an engaging format and provided the child with visual, auditory and motor input, and allowed the child to learn at his/her own rate with

as much repetition of the material as needed (Coles et al., 2007). Similarly, a computerized attention training with children with FASD showed improvements in distractibility, sustained attention, divided attention, working memory, and math and reading fluency tasks (Kerns et al., 2010).

- An intensive youth outreach and support program for adolescents with FASD had a positive impact on areas of safety, relationships, school attendance, sexual health, substance use, and knowledge and use of community resources in adolescents in a northern community without an FASD diagnosis (Hubberstey, Rutman, & Hume, 2014).
- A group therapy intervention focusing on Neurocognitive Habilitation was shown to increase executive functioning and emotional problem-solving in individuals with FASD (Wells et al., 2012)

More generally, the research indicated that interventions to support individual behavior management should include environment modification, providing structure and consistency through daily routines and rules (Kalberg & Buckley, 2007; Paley & O'Connor, 2009).

Interventions and services should be available to individuals across the lifespan, be individualized, be coordinated across systems and developmental stages, and focus on the prevention of secondary conditions (Petrenko et al., 2014; Ungar et al., 2014). Furthermore, Paley and O'Connor (2009) note that to support individuals, caregivers need to have access to relevant education, training, resources and services.

Expert Consensus/Grey Literature

Other literature and reports indicate that individual supports need to be based on developmental age rather than chronological age (Benz, Rasmussen, & Andrew, 2009; Malbin, 2004), should be individualized (Kalberg & Buckley, 2007; and should focus on remediating primary disabilities with targeted interventions for memory, information processing, academic skills, social skills, attention, motor skills, and executive functioning and visual strategies (Koren et al., 2014; Paley & O'Connor, 2011; Kalberg & Buckley, 2007). Supports should focus on interdependence, not independence (Olson et al., 2009). Similar to other research, there is a need for consistency and structure in supports and services (Badry, 2009).

Focus Groups

The focus groups echoed the findings from the literature, noting the need to focus on an individualized approach, recognizing the individual's own needs and strengths and building in wrap-around case supports around those issues. To help with this process, service providers and caregivers both indicated the importance and helpfulness of having a diagnostic assessment report to use when doing case planning and supports as it often contained relevant information and strategies that informed care for the individual.

Individual support in youth and adults also involved building in self-advocacy and life skills. One model indicated as a promising practice was the FASD Action Hall (FAH) Peer Mentorship Program at the Calgary John Howard Society. Within programs, it was important that communication was intentional to build in reminders, to check-in with the client, and to help prevent crises.

Supports should be focused towards interdependence. Many supports available in Calgary are focused on short-term, intensive supports with long-term follow-up with a lower level of support.

Participants noted that early intervention was important in preventing secondary conditions and in promoting learning and success.

Summary and Recommendations

There is significant evidence to show that supports for individuals with FASD can be effective in remediating primary disabilities and preventing secondary disabilities. It is important to take advantage of such interventions to promote the individual's quality of life and to reduce future issues.

We recommend:

- The implementation of the best and promising practices for individual support in CFAN's funded programs
- New interventions (e.g., computer-based training) should be explored for their use in CFAN's funded programs

- Additional support should be given for peer mentorship programs (similar to the FAH group) in other youth and adults impacted by FASD.

Justice System

Youth and adults with FASD are over-represented in the criminal justice system as both offenders and victims (Hayes, Shackell, Mottram, & Lancaster, 2007; Herrington, 2009). The Public Health Agency of Canada (2011) estimates that 60% of those diagnosed with FASD have had difficulties with the law and the Ontario John Howard Society (2010) posits that the rate of FASD may be ten times higher in Canadian prisons as compared to the general population. This high over-representation is due to their disability, as they often have a diminished capacity to foresee consequences, make informed choices, and learn from mistakes (Binnie et al., 2013). Their involvement with the criminal justice system can lead to serious consequences, including entrenchment in a cycle of crime; increased vulnerability to be the victims of violence or mistreatment in the prison environment; and post-release adjustment problems (The New South Wales Sentencing Council, 2004). Thus, it is important to examine the evidence to prevent or facilitate these interactions with an FASD-informed lens.

Some Evidence

One study was found regarding training around FASD for Court-Appointed Special Advocate (CASA) volunteers and found that after the 3 hour training session, these volunteers had increased their knowledge of FASD, their comfort and confidence in identifying children with FASD for referral, their ability to advocate for individuals with FASD, and knowledge of services for referral (Pomeroy & Parrish, 2013).

Expert Consensus/Grey Literature

Evidence from the grey literature was more diverse. There was a recognition that court systems need to be FASD-informed: to recognize the diminished capacity of adults with FASD, to train the legal community in FASD (Institute of Health Economics, 2013; Lane Goodfellow, in press; Wirzba, 2013). As well, individuals with FASD need support to get through the legal process. This support may include legal continuity; use of plain language; use of alternative, extra-

judicial measures where possible; recording of statements (Institute of Health Economics, 2013; Lane Goodfellow, in press; Roach & Bailey, 2008). The presence of FASD should be considered in the early stages of the judicial process ((Institute of Health Economics, 2013; Lane Goodfellow, in press; Roach & Bailey, 2008) and to meet the client where they are at and understand where they are coming from rather than confining knowledge about the issue to 'legally relevant facts' (Boulding & Brooks, 2010).

Focus Groups

Evidence from focus groups aligned with the grey literature. Participants indicated that it was important to be able to recognize FASD in a legal setting as many people came to the court system without a diagnosis and to provide training for the legal community about FASD and how to serve individuals with FASD. Service providers recognized that there was a need to advocate for individuals with FASD as the difficulties of FASD may lead to lack of comprehension, improper sentencing, and parole breeches and thus, having an advocate with them could help explain their behaviors and needs to the legal community. In many cases, participants indicated that alternative measures could be decided upon by working with the Crown to ensure that both the client and public will be safe (e.g., addictions treatment, anger management, working with a service agency).

Participants noted that it was important to build trust with their clients, even beginning the relationship when the individual is in remand or jail so that they can work to meet their individualized needs when they are released. Other strategies included taking notes during the meetings so that clients had a physical copy of the information to review and could use it to rehearse.

Summary and Recommendations

There is limited evidence available to support interventions in the criminal justice system. However, anecdotal evidence reveals that FASD-informed practice within the legal system requires training for legal professionals and continuous support from service providers who can act as advocates for the individual.

Financial Management

Financial management is an important consideration for supporting individuals with FASD, as they often have difficulties with numbers, abstract concepts, as well as adaptive life skills such as budgeting and planning.

Expert Consensus/Grey Literature

There is limited academic research in this area, however the grey literature indicates that adults with FASD may need support for applying for financial assistance (e.g., AISH, PDD), assistance with money management, and support and advocacy (Pei et al., 2015; Streissguth, 1998).

Focus Groups

Information from focus groups echoed the grey literature, indicating a strong need for money mentorship or trusteeship. The Calgary John Howard Society was planning to test a model of money mentorship for individuals with FASD that included group training, individual mentorship and budgeting, trusteeship, and real life experiences at financial institutions (e.g., training on an ATM, talking with bank advisors, etc.).

Summary and Recommendations

More research in this area is needed, however it is important to provide financial support for individuals with FASD based on their needs. It could be supporting them in applying for AISH or PDD or, on the other end of the spectrum, full trusteeship.

Families/Caregivers

It is extremely important to support families and caregivers whose families are impacted by FASD, as part of CFAN's mandate within the community and as a response to the research. Training and education for this population may be different than that for service providers and other professionals. Caregivers indicate that they need practical recommendations that they can adapt based on their individual needs and that of the individual for which they are caring.

Good Evidence

There is good evidence to support the need for stability in home life and to reduce the number of placements for children with FASD through training, support and funding for biological, foster, and adoptive parents (Brown & Bednar, 2004; Pelech, Badry, & Daoust, 2013;

Streissguth, 1997; Streissguth et al., 1998). It is extremely important to support caregivers through counseling, self-care, peer parent support networks, and respite (Brown & Bednar, 2004; Carmichael Olson et al., 2009; Doig, McLennan, & Urichuk, 2009; Hastings & Beck, 2004; Lwin, Schatia, & Black, 2011; Paley et al., 2006; Paley & O'Connor, 2009; Sanders & Buck, 2010; Singer, Ethridge, & Aldana, 2007; Whyte, 2010; Wilton & Plane, 2006).

Moderate Evidence

There is moderate evidence to show that caregivers need educational resources and training (Bertrand, 2009; Shepard & O'Neill, 2012), especially training that supports their own attitudes and parenting styles as well as their responses to their child's behaviors (British Columbia Ministry of Children and Family Development, 2009; Carmichael Olson, Oti, Gelo, & Beck, 2009; Shepard & O'Neill, 2012). Support services for families are also helpful (Chudley et al., 2005; Streissguth & O'Malley, 2000).

Parents and caregivers can be helpful in supporting their own children's success (Ladd, Profilet & Heart, 1992). A study of a social skills training intervention showed that parent facilitators were an essential component of improved social competence (Frankel, 2005).

The Coaching Families intervention (Leenaars et al., 2012), which provides support, education, advocacy, and referrals to families with children with FASD, was shown to be effective in decreasing family needs and increasing goal attainment (pre- and post- intervention). Other strategies for parental support may include problem-focused management exercises (Bertrand, 2009; Carmichael Olson et al., 2009; Kim, Greenberg, Seltzer, & Krauss, 2003).

Some Evidence

The Step by Step program and PCAP programs have shown effectiveness for working with parents affected by FASD or at risk of having a child with FASD. Both programs are based on mentorship. The PCAP program was effective in improving connections to services, increased contraception use, decreased substance use, and stable housing (Grant, 2001 in Denys et al., 2011) and the Step-by-Step program was effective in helping clients reduce their needs and achieve their goals (Denys et al., 2011).

More generally, training is linked to more successful placements, improved stability of placements, and reduced caregiver stress (Chamberlain et al., 2008 in Muhajarine et al., 2013; Petrenko et al., 2013; Pelech, Badry, & Daoust, 2013) All caregivers should receive training, support and respite to provide them with important tools for managing children and adolescents with FASD and to help reduce stress and prevent burnout.

Expert Consensus/Grey Literature

Support workers should help parents plan for the future and can be effective in supporting caregivers by understanding the challenges of FASD, building trusting relationships, making observations of behaviors and using this information to avoid negative judgments and feelings of frustration with the client/family and to instead adjust their approaches to create a better fit (College of New Caledonia, 2013).

Focus Groups

Focus groups with service providers and caregivers reiterated what was found in the literature. They stressed the importance of respite for caregivers and noted that there was a continuing gap in Calgary for trained, consistent, and available respite supports. Caregivers noted that they needed access to additional training and resources and awareness and access to supports that are FASD-informed.

As well, caregivers stressed that they needed options for supporting their children when the current activities and strategies are not working, for example supportive housing. They also needed supports for themselves, including peer support groups, help with advocating, mental health supports, and other natural supports.

Building natural supports was seen as important for supporting the individual and the family. Building natural supports takes commitment and time, consistency, and educating the supports about the individual and their needs and strengths. Natural supports can reduce social isolation and reduce victimization.

Summary and Recommendations

There is significant evidence to show that there is a need for support and training for caregivers and that FASD-informed practice among service providers will support caregivers in their role.

Recommendations in this area include:

- Investment in respite services that are consistent, trained in FASD, and reliable
- Training for caregivers on FASD and support practice should be available and accessible
- Investment in transitional services for youth and adults for FASD

Housing

A growing body of research on the primary and secondary disabilities of FASD has identified parallel life challenges to those of the homeless population (Gelb & Rutman, 2011; SAMSHA, 2007; Solliday-McRoy, 2004). Furthermore, Streissguth et al. (1996) found that 80% of adults with FASD over the age of 21 years are unable to live independently because of their challenges around managing money, poor judgment, decision-making, getting medical care, and interpersonal relationships. Thus, housing is an important need for individuals living with FASD and their families. There are limited housing options available in Calgary for adults living with FASD and both service providers and caregivers expressed concern around where their client/child would go in adulthood, especially with the reduction of other support services in adulthood.

Some Evidence

There is some evidence to indicate that adults with FASD may not be able to live independently or may require additional supports to be successful in their housing. This will depend on their adaptive and life skills as well as their secondary conditions (Badry et al., 2015; Wirzba, 2013)

Expert Consensus/Grey Literature

The grey literature around housing and FASD indicates that service providers and support networks need to be active in supporting adults in their housing. In a study on housing for individuals with severe mental illness, Whitley, Harris, and Drake (2008) found that service providers need to continuously monitor and address safety issues. Badry and colleagues (2015) found that individuals with FASD need support with guest management and security. Best practices for support in other areas should be implemented within the housing setting (e.g., housing rules should be in plain language, labels on the cupboards, instructions for loading the

dishwasher, etc.). Financial management or trusteeship is also important to make sure that rent is paid on time and that the individual receives assistance with budgeting (Badry et al., 2015).

In a report on supportive housing for individuals with FASD, Burns (2009) noted that housing programs should offer on- and off-site supports, promote community and a sense of belonging. They should also be flexible and make necessary and appropriate accommodations for the individual and work to prevent secondary disabilities. Burns (2009) suggests taking a client-centered approach where housing staff work with community providers to engage individuals, address their immediate needs, connect them with community supports, and act as a liaison with their landlords.

Focus Groups

Focus groups with service providers and caregivers indicate that it is important to give the individual a choice about the type of housing that they live in and that housing should be matched to the needs and desires of the individual. Housing programs and staff should be FASD-informed to ensure that appropriate accommodations are made for each individual. As well, service providers noted that for Calgary Housing programs, the SPDAT is not an effective assessment tool for people with FASD and other cognitive disabilities so another tool is needed.

Summary and Recommendations

Based on the available evidence, we recommend that:

- An investment is made into supported housing for individuals living with FASD
- Appropriate housing options are available for youth transitioning to adulthood, as this is a period when caregivers may become overwhelmed
- Financial management should be put in place for individuals living in housing programs
- Training should be done to inform the housing sector and housing providers/staff about FASD and the needs of individuals living with FASD in housing

Employment

Many individuals with FASD may struggle with finding stable and sustainable employment. Due to their disability, individuals with FASD may not be able to keep steady schedules without support, may have limited attention spans and difficulties with memory, and may have

difficulties in learning new skills and retaining their employment. Thus, there is a need to support individuals with FASD into employment that matches their skills, and to ensure that the correct natural and environmental supports are put into place to promote employment sustainability.

Some Evidence

A report by the National Mental Health Association (n.d.) describes several models of supported employment services to be used to support people with psychiatric disabilities.

These potentially could be used for individuals with FASD as well:

- The Job Coach Model, where a job coach assists an individual with finding a job and provides on- and off-site job support. The Job Coach may also work with the consumer, employers, or other stakeholders to ensure that everyone understands the individual's needs and strengths; this helps to facilitate a successful work experience.
- Choose-Get-Keep-Leave, a skills-oriented approach where, with the help of a service provider, an individual chooses a job based on their desires, needs, and interests. Then they work to get a job that fits that description, keep the job with ongoing support, and finally, to leave the job for another experience that contributes to their future success.
- The Assertive Community Treatment (ACT) approach involves interdisciplinary team that provide intensive case management as well as psychiatric support and other services, including an employment specialist to work with the individual to find/provide supported employment.
- Individual Placement and Support (IPS) integrates vocational and clinical services and uses six principles to support employment: goal for competitive employment, rapid job search, integration of rehabilitation and mental health, attention to the client's preferences, continuous and comprehensive assessment, and time-unlimited support.
- The Menu Approach combines four principles: that work offers benefits besides financial compensation; persons with mental health issues can participate in and benefit from meaningful, paid work; individuals should be able to choose from a "menu" of employment options; experience in different kinds of paid work is an important part of developing long-term employment in competitive settings.

Expert Consensus/Grey Literature

The grey literature reiterates several of these findings. Pei and colleagues (2015) note that rapid placement is important as it is easier to keep an individual with FASD engaged if they are working. It is also effective to determine and reinforce the individual's motivation for employment to keep them on track. Intensive supports are also needed to retain the individual in their employment. On-site supports should be available during the initial stages of the employment to help overcome any obstacles, guide behaviors, educate employers and co-workers. The length of time intensive and more long-term supports should be flexible and depend on the individual's needs. Wrap-around supports should also include access to other community resources.

Pei and colleagues (2015) continue with other strategies, including:

- enacting a regular work schedule to promote regular work attendance, minimizing absenteeism, and reducing termination
- Using clear, concrete language
- Keeping up regular communication to keep engagement and build rapport
- Ongoing staff training to ensure an understanding of FASD.

Focus Groups

Focus group participants talked about several principles of job training and employment that met the needs of their clients, including:

- Rapid placement, which capitalizes on the motivation of the client and their engagement in the program, following the idea that clients need to be “ready, willing, and able”.
- Regular, routine work can help clients who need structure
- Need to build supports for the individual, not the diagnosis
- Natural supports should be built-in and encouraged to help create continuous sustainable support for the individual, even after the program has ended
- Focus on strengths
- Educate the work team about the individual's strengths and needs in the position, including any accommodations

- Work to build skills for independence (e.g., through volunteer work)
- Need shorter-term focused interventions and then longer-term, minimal supports

Summary and Recommendations

While there is not robust evidence to support the effectiveness of the models outlined above, it is likely that individuals with FASD could benefit from employment and job training services that incorporated the principles.

- CFAN should work to support engagement of individuals in meaningful employment through implementation of these principles in their existing programs, where needed.

Health

It is important to consider the healthcare interactions of individuals with FASD as they move throughout childhood, adolescence, and adulthood, for example around sleep, medications, and seeing the doctor. Their needs will change as they grow older, and individuals with FASD may be able to find some behavioral management through medications and other health interventions.

Moderate Evidence

There is moderate evidence to show that medication can help with some of the behavioral issues associated with FASD (Doig et al., 2008; Snyder et al., 1997).

Some Evidence

A study of 19 women with FASD showed that providing individualized intervention to connect them with systems of care resulted in outcomes of decreased alcohol/drug use, increased housing and use of contraceptives, and improved medical and mental health care services (Grant et al. 2004).

Expert Consensus/Grey Literature

There were several areas of health evidence for individuals and families affected by FASD, including mental health, sexual health education, physical health, and sleep.

For mental health, prevention or early intervention is important to improving lifelong health and quality of life (Famy, Streissguth, & Unis, 1998; O'Connor & Paley, 2009).

For sexual health, there is a need to plan ahead to avoid crises such as unplanned pregnancy. Individuals with FASD may be vulnerable to sexual exploitation. Sexual education must be explicit and clear, following the needs for simple language (Streissguth, 1998). Caregivers and service providers should discuss reproductive health options with the individual and should encourage long-term contraceptives rather than short-term, daily pills that may be easily forgotten (Badry et al., n.d.; Wirzba, 2013).

Assisting individuals with FASD in achieving a healthy sleep cycle is important. Jan and colleagues (2010) recommend having appropriate sleep environments, sleep hygiene, and sleep-promoting practices. Sleep environments should be adjusted to accommodate the child's sensitivity to lights and sensory stimulation. Sleep hygiene, the promotion of optimal sleep health practices through environmental management, should be addressed through the scheduling of sleep, improved sleep environment, and the use of sleep-promoting practices. Sleep-promoting practices for children with FASD may include soft, soft, simple communication with frequent repetition, ordering of activities, simple, repetitive storytelling (to increase comprehension and remove stimulation), and promote relaxing techniques before bedtime (e.g., warm bath/shower, rocking, massaging, quiet music, quiet time, etc.). All of these sleep activities will depend on the individual child and may require trial and error to achieve success. Children who do have sleep disturbances should be treated early and appropriately (Jan et al., 2010).

For physical health, Hanlon-Dearman and colleagues recommend the following for primary healthcare providers who may see children with FASD:

- Screen the child for maltreatment and advocate for placement stability for the child and education for their families to minimize or prevent further trauma (Grant, 2011);
- Monitor academic and social functioning with the family and education system;
- Educate caregivers on behavioral and medication management;
- Screen the child's communicative skills and make appropriate referrals to speech and language therapists;
- Make appropriate referrals to educational and family supports;
- Screen the child for sleep disorders and provide appropriate referrals;
- Identify and treat co-morbid health conditions early; and

- Take a team approach, based on child- and family-centred care, inter-professional collaboration, evidence-based knowledge, flexible care provision, shared communication, effective resource coordination, and integration of care.

Physical activity is also important in working towards physical, psychological and emotional benefits (Jirikowic, Gelo, & Astley, 2010).

Focus Groups

Additionally, focus group respondents noted that medication adherence can be difficult for individuals with FASD so it is important to use very concrete language (e.g., Don't say 'take 2 pills 3 times daily', Say 'Take 2 pills at breakfast, 2 pills at lunch, and 2 pills before you go to bed'). As well, service providers and caregivers can continue to advocate for their clients at medical appointments, if invited, to help ensure understanding of medical advice, to help the client explain their needs, and to help advocate for appropriate treatment.

Summary and Recommendations

It is important to set up health environments, promote healthy behaviors, and ensure that physical, mental, and sexual health provision is FASD-informed. To do this, we recommend:

- Training healthcare providers to be FASD-informed
- Creating awareness of health promoting activities for individuals with FASD

Education

Educational interventions are increasingly important for children and adolescents with FASD. Many individuals affected by FASD struggle with the social and academic aspects of their educational experience; this can lead to dropping out of secondary school, which will perpetuate future life issues. Supports can be helpful in promoting and adapting their educational experiences.

Good Evidence

There is good evidence to support several educational interventions for children with FASD, in the areas of language and literacy (Adnams et al., 2007), cognitive control (Adnams et al., 2003

in Riley et al., 2003; and mathematics (Kable et al., 2007; Kable, Taddeo, Strickland, & Coles, 2014).

Moderate Evidence

Other learning interventions have moderate evidence, including the Children's Friendship Training program (Laugeson et al., 2007; O'Connor et al., 2012), other social skills training to improve appropriate social behavior, increased social skills, and decrease problem behaviors (O'Connor et al., 2006), parent assisted adaptive functioning training (Carr, Agnihotri, & Keightley, 2010; Jirikowic, Carmichael Olson, & Kartin, 2008; Maag & Larson, 2004), and rehearsal training for improving memory with numbers for children with FASD (Loomes et al., 2008).

More generally, research has shown that caregivers are key facilitators in the maintenance and generalization of newly learned skills (Bertrand, 2009; O'Connor et al., 2006; Paley & O'Connor, 2011) and that it is important to use a unique, tailored learning profile for children with FASD (Denys et al., 2011; Kalberg & Buckley, 2007; Pretti-Frontczak & Bricker, 2000).

Some Evidence

Teachers should use short, clear instructions when working with children with FASD (Streissguth, 1998) and need to recognize a child's comprehension abilities (Alton & Evensen, 2006). Teachers should teach both visually and verbally, and should be FASD-informed (Streissguth, 1998). Teaching social skills should involve peer mentorship where the child with FASD has a peer to check in with if he/she forgets what to do. (Alton & Evensen, 2006).

Cognitive behavioral strategies may also be helpful, such as social skills training, emotional identification, coping skills, anger management, and self-talk (Green, 2007). As well, parental advocacy may be a protective factor for adolescents with FASD to stay in school (Duquette et al., 2006).

Expert Consensus/Grey Literature

Functional assessments can be used to produce individualized learning plans and to target behaviors (Badry, 2009; Kalberg & Buckley, 2006; 2007; Maag & Larson, 2004). This can involve

an identification of students' strengths and an alignment of strategies with their needs (Alberta Education, 2009).

Teachers should be FASD informed, which may include the following principles (Alberta Education, 2009; Yukon Education, 2006):

- Recognition of age-appropriate versus developmentally-appropriate tasks and behaviors;
- Preparation for transitions;
- Trying “differently”;
- Establishing structure and using concrete language;
- A recognition of the disconnect between intention and behaviors; and
- Making environmental adaptations to meet the child’s sensory processing needs.

Supports for the child should be developed with other natural supports (Alberta Education, 2009). Using a family-focused or family-centred model can assist teachers in making these connections (Yukon Education, 2006).

Classroom accommodations should be made to support the child’s learning, including preferential seating, reducing overstimulation, reduced task length, extra time for tests, access to a scribe, reminders for organizational skills, and modified learning if a learning disability is also present (Canadian ADHD Resource Alliance, 2014 in Hanlon-Dearman et al., 2015)

Summary and Recommendations

Educational environments need to be FASD-informed and focus on the child’s individual learning needs. Specific models of intervention may be effective in increasing skills in specific areas of need.

- Investment is necessary in interventions to support the child’s learning. Advocacy and training may be necessary to ensure that educational institutions and professionals are FASD-informed.

Diagnosis/Assessment

As one of the CFAN’s pillars, supporting diagnosis and assessment in the community is recognized as an important practice. Diagnosis can be difficult due to the age of the individual, the need for maternal confirmation of alcohol consumption during pregnancy, and the financial

resources required. Individuals with FASD may not be well supported in the requirements of the assessment and diagnosis process (e.g., with getting to and from multiple appointments). Waitlists can also be an issue. Furthermore, stigma and discrimination around a diagnosis of FASD can prevent individuals from seeking a diagnosis and thus, from getting necessary supports. Because diagnosis and assessment can help to identify areas of strength and challenge for the individual, can help with service planning, and can lead to financial assistance, it is necessary to provide support for individuals with FASD to get a formal diagnosis, where possible.

Good Evidence

There is considerable evaluated, non-evaluated, and grey literature evidence to indicate that early diagnosis is associated with better outcomes for individuals with FASD and their families and can act as a protective factor against the development of secondary conditions (Benz, Rasmussen, & Andrew, 2009; Stade et al., 2006; Streissguth et al., 2004; Carmichael Olson, Jirikowic, Kartin, & Astley, 2007; Koren et al., 2014). There is good evidence to show that the diagnostic assessment can improve options for intervention and help to reframe problematic behavior (Malbin, 2004).

Proper diagnosis requires multi-disciplinary diagnostic teams (Astley, 2014) and for adults, an embedded team model is better because the necessary supports are already available with supports and awareness (Temple, Ives, & Lindsay, 2015).

Moderate Evidence

There is moderate evidence to support the notion that a careful assessment of each individual's capacities, not just a diagnosis of FASD is needed (Peadon, 2009).

Some Evidence

Paley and colleagues (2009) found that training is needed for healthcare providers to support referrals for assessment and diagnosis, especially as early referrals from those who have interactions with the child can lead to early diagnosis (Carmichael et al., 2007).

Ens and colleagues (2010) and Hanlon-Dearman and colleagues (2014) investigated the effectiveness of an FASD assessment telehealth program in two rural and remote communities

in Manitoba. The telehealth program was regarded as successful by those interviewed as it could take place within their own communities, involving more individuals from the child's support network to create a stronger network, and could be used to reduce transport and other costs. This model presents some potential for extending equal access for assessment and diagnosis to rural communities in Alberta.

Summary and Recommendations

There is overwhelming evidence to indicate that diagnosis is an important part of providing support for individuals with FASD and that early diagnosis is key to reducing the primary and secondary impacts of FASD.

- As case management can be improved through the use of an assessment to guide case planning, we recommend that CFAN make an investment in diagnostic and assessment services in the Calgary region, both rural and urban.
- Training and education are needed to help professionals who work with children in early childhood are able to recognize the signs of FASD and can make early, appropriate referrals.

Organizational Intervention

Some Evidence

There is some evidence to support the need for collaboration between service providers and community agencies to promote communication and intentional planning, common goals, interventions, and a consistent approach (Nova Scotia Health Research Foundation, 2012; Stonehocker, 2012; Walls & Pei, 2013). Evidence from disability research indicates that to support youth with complex needs who use multiple services, there is a need for services that are: multi-level, coordinated, continuous over time, negotiated with users, provided along a continuum from least to most intensive, and that have been shown to be effective; these services are more likely to meet long-term needs (Ungar et al., 2014).

Expert Consensus/Grey Literature

More general information from the grey literature indicates that organizations need to invest in training for FASD for their service providers (Badry, 2013; Walker, 2014), need to educate and

support staff to engage in reflective practice, work from an FASD-informed approach, be trauma-informed, and focus on harm reduction (College of New Caledonia, 2013) and strengths (Rutman & Van Bibber, 2010; McNeill, 2014).

Cultural components for interventions should be researched and implemented (Yukon Education, 2006). There should also be support for staff to deal with vicarious trauma, burnout, and stress (Guarasci, 2013; Yukon Education, 2006). Continuing professional development and training is needed in FASD-specific areas as well as complex case management, and developmentally appropriate approaches (Badry, 2013).

Service organizations should refrain from limiting services based on missed appointments, a client's discomfort with formal institutions, a lack of transportation, the location of residence, and/or an inability to understand or meet expectations (College of New Caledonia, 2013). This will support individuals with FASD who often have difficulties with such matters and thus could have their services terminated as a result.

Focus Groups

Data from focus groups indicated that training and experience was necessary for service providers to be most effecting in supporting individuals with complex needs. To help determine appropriate levels of education, training, and experience, standardized competencies could be used to help promote success.

Another organization also noted that the organizational culture could be very helpful for allowing change based on best practices and the ability to try new things within their practice.

Summary and Recommendations

Organizations should promote training, education, and support for their staff. This will ultimately impact positively on their clients.

Recommendations include:

- Changing job requirements for FASD-specific service agencies to need formalized training (e.g., Bow Valley College FASD program)
- Ensure appropriate mental health supports are available for staff
- Invest in training and education for staff

Addictions & Mental Health

Individuals with FASD may face issues with addictions and mental health. Despite this risk, traditional treatments for addictions and therapies for mental health issues are often unsuccessful and inappropriate for individuals with FASD. For example, motivational interviewing is often seen as a best practice for certain cognitive therapies, it may be too cognitively challenging for some individuals with FASD and therefore will be unsuccessful (Backer & Howard, 2007). Thus, there is a need for more research into what works best for individuals with FASD who have issues with mental health and/or addictions.

Moderate Evidence

Addictions treatment for individuals, especially women, with FASD should be relationship-based (Rutman et al., 2010). There should also be mandatory FASD training for professionals working in the addictions/mental health sector (Grant, 2004; Grant, 2007).

Some Evidence

Accommodations within existing addiction treatment programs that may support individuals with FASD in their success include: re-framing problem behavior; modifying brief motivational techniques; FASD-informed group facilitation; FASD-informed treatment planning (e.g., concrete language, small steps, checks for understanding) and activities (tailored to developmental age); flexibility and support for transportation, attendance, duration of program to account for the individual's needs and disability; changes to the physical environment to account for any sensory processing needs; one-on-one tailored treatment; and/or enhanced case-management (Boyd et al., 2008; May et al., 2008; Middleton et al., 2009; National Treatment Strategy Working Group, 2008; Opie, 2008; Winter, 2008).

Expert Consensus/Grey Literature

Treatment for individuals with FASD with addictions issues should be trauma-informed, deal with co-occurring issues (e.g., mental health), work from a harm reduction strategy, support families, remove stigma and blame, and include cultural accommodations. Within a harm reduction strategy, service providers should work to reduce isolation, provide access to and support for good nutrition; support access to needle exchange programs; support access to

birth control; reduce risk of contracting HIV/AIDS or STIs; support participants to ensure their safety and the safety of their family if/when they decide to use substances; and assist with identifying/building supportive networks (College of New Caledonia, 2013).

Summary and Recommendations

More research in the area of supported addictions treatment for individuals with FASD is needed. There is also a need for advocacy for FASD-informed addictions treatment in Calgary.

What does success look like?

Based on the focus group interventions, participants indicated that success for their clients was based on the client's individualized goals, but could include a sense of belonging or security, engagement with the community, independence or interdependence, reduced interactions with systems, becoming more empowered, reducing stress, having better supports, and working with an FASD-informed network. It is important to continue to explore this area to better understand what success looks like and how it can be attained.

Gaps in Supports

Many gaps in supports were identified within the focus groups and through the survey. The major themes were:

- **Gaps in employment** included limited options for individuals with FASD who need more pre-employment support and for those who fall between the gap of Prospect Human Services and PDD funding.
- **Gaps in housing** included a lack of supported housing options in Calgary and a lack of FASD-informed service provision in housing programs.
- **First Nations, Métis, Inuit supports** are needed, especially on reserve.
- **Gaps for caregivers** included an overwhelming need for trained respite. The lack of respite care in Calgary can lead to isolation, high levels of frustration, and burnout.
- **Gaps in youth and adult services** in Calgary. There are very few options and caregivers are stressed about being able to care for their adult child with FASD as they age. Youth

services are needed, especially as individuals with FASD (like most teenagers) will need extra support as they go through different developmental stages (e.g., puberty).

- **Gaps in addiction and mental health services.** Currently, there are limited effective options for addictions or mental health services for individuals living with FASD. Many of the traditional methodologies for such programs do not work for most individuals with FASD because of the need for autonomy, group work, verbalizations, etc.
- **Gaps in services, in general.** There is a need for more centralized services where an individual's information can be accessed throughout the system, along with their strengths and weaknesses and the best strategies for support. As well, the promotion of [of] collaborative case management between systems would be effective in decreasing silos and increasing coordinated access to information and referrals.

Overall Recommendations

The following over-arching recommendations are based on the evidence outlined above as well as CFAN's priorities:

1. **Building Capacity within our Community:** The Calgary region needs education and training for service providers and caregivers to use and adapt evidence into their own practices through flexible strategies. Sectors and services should be FASD-informed and should develop awareness of what FASD is, how to recognize it, and how to support individuals and families with FASD. Service providers and caregivers who work specifically with individuals and families affected by FASD should also receive training to build their skills and experience in providing support. Given their expertise and vast network of professionals, CFAN and its funded agencies are able to lead education and training activities in the community and the systems-of-care which impact those with FASD to better support individuals and families with FASD. CFAN should also provide professional development opportunities to its funded agencies to ensure evolving best practices and evidence are instilled into current practice.

2. **Recognizing the Impact of Diagnosis and Assessment:** The process of diagnosis and assessment is crucial for individuals living with FASD and should be a priority for early intervention. Multidisciplinary diagnosis and assessment reports, based on the Canadian Guidelines, can provide important information for families, caregivers, and service providers to build support and success with individuals with FASD. Obtaining diagnosis and assessment should be a goal to support individuals affected by FASD. However, in cases where diagnosis has not been obtained, service providers and families must be trained to provide support without the help of a diagnostic assessment. This support should be FASD-informed when developing strategies and solutions for the complex issues faced by those with FASD. CFAN is well-poised to support individuals and families through the assessment process and will fund agencies who know how to implement the diagnostic assessment into their practice as well as to support individuals who do not yet have a diagnosis.
3. **Building Resiliency:** Individuals with FASD may need targeted supports to build their capacity for independence and interdependence. Families and service providers should work together with a wrap-around approach to meet the needs of these individuals with intensive, focused support to build on the individual's strengths. Over time, these supports can evolve as vulnerabilities are reduced, solutions are found, and goals are met, recognizing that varying levels of support may be needed throughout the lifespan. CFAN should work with community partners, including their funded agencies, to build supports that heighten resiliency in individuals with FASD to help build interdependence.
4. **Spectrum of Supports:** Because of the individualized nature of FASD, a spectrum of supports is needed in the Calgary region's system-of-care to ensure that the right supports are given at the right time. CFAN and its funded programs should work to ensure a tailored approach - that necessary supports are available for individuals and families affected by FASD and that low-, mid- and high-acuity needs are able to be addressed through community programming. Supports should be adaptable, based on

the level of need, pro-active rather than reactive, and focus on the prevention of secondary and tertiary disabilities.

5. **Commitment to Support Communities affected by FASD:** There is limited information on best practices for supporting specific sub-groups of individuals and families affected by FASD, including Aboriginal communities and refugee and immigrant communities. CFAN and its funded agencies are well-poised to partner with these communities and the service agencies who work with them to bridge gaps in culturally-appropriate education, services, and awareness.
6. **Developing Targeted Programming:** CFAN and its funded agencies should work with their community partners to develop targeted programming for youth and adults with FASD across sectors and systems which they may access, including: the criminal justice system, child welfare system, physical and mental healthcare, financial assistance and employment, and housing.
7. **Commitment to Caregiver and Natural Support:** Caregivers play an extremely important role in supporting individuals with FASD and should receive training, access to services and resources, and respite care. Given its placement in the community, CFAN can act to meet the needs of caregivers and natural supports of individuals with FASD by providing programming, support groups, and professional development opportunities.
8. **Commitment to Best Practices:** CFAN has committed to building FASD-informed practice within its funded agencies and throughout the community, through the collection of the available evidence on best practices for intervention throughout the lifespan for those impacted by FASD. CFAN should continue to work towards implementing these and evolving best practices into its funded programming and ensure that its funded programs align with these best practices.

The following program-level recommendations are based on the academic and grey literature as well as the survey and focus group data:

- 1. Service providers should deliver supports to families and individuals using the following principles to inform their practice:**
 - a. Flexibility
 - b. Individualized care (based on collaboration with natural supports and other service providers and information from the diagnostic assessment, if available)
 - c. Structure (using memory strategies, time management strategies, schedules, reminders, etc.)
 - d. Strength-based supports
 - e. Building resiliency, self-advocacy, and interdependence skills
 - f. Concrete language
 - g. Consistency and repetition
 - h. Trauma-informed care
 - i. Early intervention
 - j. Prevention of secondary and tertiary disabilities through focused and pro-active support (e.g., financial management, education, employment, justice, mental health and addictions, etc.)
 - k. Pro-activity
- 2. Service providers should be open to collaborative practice, professional development opportunities, and to trying new interventions, based on evidence from the literature or other practitioners (e.g., technology).**
- 3. Service providers should strive to ensure that other service providers and systems in contact with the individual and family understand their needs and strengths so that informed decisions for support can be made.**

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