



SASKATCHEWAN POPULATION HEALTH AND EVALUATION RESEARCH UNIT

**Evaluation of the Government of Saskatchewan's
FASD-Related Services:
Cognitive Disabilities Consultants and
Community-Based Support Programs**

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EXECUTIVE SUMMARY

Many initiatives support individuals with cognitive disabilities in the province of Saskatchewan. At the request of the Ministry of Health, we evaluated two types of initiatives: (1) the Cognitive Disabilities Strategy (CDS) and regional Cognitive Disabilities Consultants (CDCs) who work with families living with cognitive disabilities to develop behavioural support plans and access funding to address unmet needs; and (2) four community-based support programs: two mentoring programs for adults with cognitive disabilities (run by Aboriginal Family Services Centre in Regina and the Central Urban Métis Federation, or CUMFI, in Saskatoon); the FASD Network of Saskatchewan's Family Support Program, which provides information, peer support, and advocacy for families in the Saskatoon area; and the Regina Community Clinic's Life Skills and Addictions Program for adults with FASD, which offers both group programming and individual support. The CDCs and the first three community programs listed are funded by the CDS, while the Community Clinic's program is funded by the Ministry of Health through the Regina Qu'Appelle Health Region.

The purpose of the evaluation was to describe each of these five programs and how they are perceived by clients and other service providers, the strengths of each program and the challenges staff face in delivering services, the program impact from the perspectives of program staff, clients, and other service providers, and suggestions for enhancing program effectiveness.

Between September and December 2013, we conducted semi-structured interviews and focus groups with a total of 82 individuals: the CDCs; program administrators and frontline staff from each of the support programs; clients of the CDCs and each of the programs; service providers associated with the CDS; and representatives of partner agencies for each of the programs.

The CDS itself, through the services of the CDCs and the funding it provides to individuals and families, was identified as having three key strengths: the knowledgeable, helpful consultants; the inter-ministerial foundation of the program that facilitates consultants working across sectors; and the fact that the funding, as intended, enables clients to address previously unmet needs, such as providing a mentor and accessing programming, therapies, and respite. However, several significant challenges were also noted: frequent and lengthy delays in the processing of applications and claims; unnecessarily complicated, time-consuming and onerous application and renewal processes; dissatisfaction with the amount of funding, including the amount available and what is covered, income cut-offs, inconsistencies and lack of clarity around what can be claimed; confusion about the roles and responsibilities of the various team members, organizations, and service providers, including the consultants; desire for better communication and more transparency; difficulty finding qualified mentors; a need for standardization across regions; difficulty accessing services in rural areas; and a need for more consultants.

The four community support programs are essentially operating as intended, although most have struggled with staff turnover. They are clearly addressing a great need. All are at capacity and would like to be able to accommodate more clients. While there are some differences in the ways the programs run, they share several strengths: dedicated, compassionate staff who take a flexible, holistic approach to meeting clients' needs and who help them connect with other agencies and organizations. Clients also benefit from the other services and amenities offered by each particular organization.

The programs also face some common challenges: the nature of cognitive disabilities themselves makes their work unpredictable and sometimes frustrating and stressful; many clients lack external resources, especially supportive housing, making them harder to reach and adding to their instability; many of the 'systems' that program staff try to help clients navigate do not accommodate individuals with cognitive disabilities well, and there is a need for greater understanding of these disabilities in many other agencies and organizations. Finally, funding limitations mean that services can only be offered during regular business hours and frontline staff are paid relatively low wages with few benefits, leading to high turnover in most of the programs, which negatively affects the quality of services. Those interviewed about the two programs that do not provide mentors indicated that there is a need for more one-on-one support, like that provided by the other programs. General agreement was expressed by those we interviewed that the programs merit expansion, so that more of the many cognitively disabled individuals who are eligible for and need one-on-one support are able to receive it.

The impact of all these programs, including CDS, is difficult to gauge, partly because of the evaluation methodology, and partly because the nature of cognitive disabilities can make it hard to document clear progress. Much of what support programs do is prevent problems in clients' lives, which is unobservable. However, all those interviewed agreed that the emotional and informational support offered by consultants and mentors, along with improved access to other services and programs, have greatly improved the quality of life for many clients. Many questioned where clients would be and how they would manage without the program. Specific examples of impact included: families experiencing healthy pregnancies; parents regaining custody of their children; clients staying in school, finding and keeping employment, obtaining appropriate housing and living independently; reduced strain on families; clients who had been involved in the justice system completing probation orders and not re-offending; improved access to health care and medications, resulting in better treatment of mental and physical illnesses; and clients managing their addictions. A global impact is social inclusion: individuals, many of whom are among the most marginalized in our society, feel cared about, develop a sense of belonging, and are able to function better in their communities.

The impact of these programs extends beyond improving the lives of the clients and their families, as they are also in many cases facilitating the work of other agencies and organizations (e.g., justice

system, health services). Furthermore, by keeping clients out of jails, hospitals, and emergency rooms, helping some of them to live independently and to be employed, and supporting healthy pregnancies and parenting, community-based support programs have the potential for significant cost savings to our society. Cost-benefit analysis of these programs would be a worthwhile focus for future evaluations.

GLOSSARY OF ACRONYMS

ABI	Acquired Brain Injury
AFSC	Aboriginal Families Services Centre
ASD	Autism Spectrum Disorder
CDC	Cognitive Disabilities Consultant
CDS	Cognitive Disabilities Strategy
CLAS	Community Living Association of Saskatchewan
CLSD	Community Living Service Delivery
CUMFI	Central Urban Métis Federation (1993) Inc.
DLSA	Daily Living Support Assessment
FASD	Fetal Alcohol Spectrum Disorder
FSIQ	Full Scale Intelligence Quotient
RCC	Regina Community Clinic
SAC	Saskatchewan Abilities Council
SACL	Saskatchewan Association for Community Living
SAID	Saskatchewan Assured Income for Disability
SAP	Saskatchewan Assistance Program
SSILC	South Saskatchewan Independent Living Centre

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1.0 Purpose and Objectives

The purpose of this project was to evaluate services funded by the Government of Saskatchewan to support individuals and families living with cognitive disabilities, specifically, the Cognitive Disabilities Strategy (CDS) and regional Cognitive Disabilities Consultants (CDCs) and four community-based support programs.

The evaluation objectives were to describe each of these five programs and how their services are perceived by clients and other agencies, the strengths of each program and the challenges staff face in delivering services, the program impact from the perspectives of program staff, other agencies, and clients, and suggestions for enhancing program effectiveness. These objectives were addressed qualitatively by interviewing staff, clients, and partner agency representatives from each of the programs.

2.0 Background

Each of these five sources of support services for people with cognitive disabilities—the CDS and the CDCs, who provide services to individuals through the province’s health regions, and four community-based organizations, two located in each of Regina and Saskatoon—is described in the next section.

2.1 Cognitive Disabilities Strategy

The provincial Cognitive Disabilities Strategy (CDS) was established in 2005 with the aim to “improve the availability of assessment and diagnosis services; provide services to address the unmet needs of people with cognitive disabilities and their families; provide training opportunities to enhance the knowledge and skills of people who provide services to individuals with cognitive disabilities; and enhance Fetal Alcohol Spectrum Disorder prevention intervention initiatives throughout the province” (Saskatchewan Ministry of Health, n.d.).

In addition to providing block funding to three community-based organizations that offer services to people with cognitive disabilities (Aboriginal Family Services Centre, CUMFI, and FASD Support Network of Saskatchewan), the CDS also gives direct funding to individuals with cognitive disabilities for services that they currently do not receive, such as respite care, additional therapy or mentorship. The CDS seeks to fill a gap in services for individuals with unmet needs and for those who do not meet the mandate of any other service providers. A diagnosis of a cognitive disability is not required to be eligible for assistance. At the time of this evaluation, the CDS employed a coordinator and twelve Cognitive Disabilities Consultants (CDCs) across the province. Each consultant is responsible for one or more health regions and “works with the support teams of individuals to provide suggestions and training that will support an individual to achieve his or her goals; and provide individual and group training to enhance knowledge and skills of service

providers, caseworkers and families concerning cognitive disabilities, developmental challenges and behavioural support strategies” (Saskatchewan Ministry of Health, n.d.). Consultants can also help individuals without any supports to fill out the application form to access funding from CDS.

An internal report provided to us by a CDS policy analyst in October 2013 summarizes the characteristics of CDS clients as of that time. The caseload has increased steadily, from 88 in 2006-07 to 784 in 2012-13. Almost 64% of the clients were male, about 14% were Aboriginal, and 91% were single. Just over half had an active CLSD (Community Living Service Delivery) involvement. While the initial intent of CDS was to provide benefits for individuals between the ages of 6 and 24 years, a quarter of clients were over 24, and 4.5% were under 6. In terms of disability, almost half of clients have been diagnosed with one of the three main disabilities that CDS was intended to focus on: Fetal Alcohol Spectrum Disorder (FASD) (7.9%), autism (28.5%), or acquired brain injury (ABI) (8.2%). The largest group (49%) is classified simply as having “cognitive delay.” The average Daily Living Skills Assessment (DLSA) score was 3.2.

CDS clients use the funding they receive to help with a variety of previously unmet needs. The most frequent is hiring a mentor (57.6% of clients), followed by disability-related programming (22.6%), various therapies (19.6%), respite (18.5%), and other needs, such as special equipment, dietary needs, travel, and incontinence supplies.

2.2 Community-based organizations

The Aboriginal Family Services Centre in Regina and CUMFI in Saskatoon have both been funded by the CDS since 2007 to provide mentoring services to adults with FASD or ABI. The FASD Support Network of Saskatchewan started its Family Support Program for Saskatoon-area families living with FASD in 2011-12, with funding from the CDS and the Regina Community Clinic established a Life Skills and Addiction program for adults with FASD in 2011, funded by the Ministry of Health through the Regina Qu’Appelle Health region.

Aboriginal Family Services Centre

Aboriginal Family Service Centre (AFSC) is a community-based non-profit organization dedicated to helping families and children in Regina through a variety of culturally relevant programs and services. Activities include support in the following; education, training and employment, advocacy, crisis intervention, transportation, visitation supervision, and mentorship. Since 2007, AFSC has received funding from the CDS for its mentoring program for older youth and adults with cognitive disabilities, mainly FASD and ABI. At the time of this evaluation, the mentoring program employed three mentors (with a fourth hired after data collection was complete) and one team leader, who also holds a caseload. The program activities include building life skills, coping and problem solving skills, assistance in accessing health care, employment and education, housing and income assistance, crisis intervention, and social interaction.

Central Urban Métis Federation (1993) Inc. (CUMFI)

CUMFI is a community-based, Métis owned and operated organization located in the inner core of Saskatoon. Over the past 20 years, CUMFI has implemented initiatives in a variety of areas including economic development, social housing, recreation, justice, health and education. In 2007, with funding from the CDS, the organization began administering the CUMFI Wellness Centre, a mentoring program for individuals aged 15 and over who have FASD, ABI or other cognitive disabilities. CUMFI utilizes this funding to employ a full-time project coordinator and five full-time mentors (a sixth mentor is funded by CUMFI). Other facilities at CUMFI include a drop-in resource centre which is open from 9 to 5 weekdays and offers access to a telephone, computers, and games; showers, an exercise room, and a kitchen. Mentors meet individually with clients to help them as needed with accessing health care, housing, employment, transporting and accompanying them to do errands and keep appointments, and providing companionship and positive role models. In addition to this one-on-one support, occasional group activities are offered, from cultural and recreational outings to crafts and cooking.

In 2012, CUMFI hired a mental health coordinator who works with the Wellness Centre clients as well as other programs, providing counseling and helping connect clients with mental health resources. While a Métis organization, CUMFI serves non-Aboriginal as well as Aboriginal clients.

FASD Support Network of Saskatchewan

The FASD Support Network of Saskatchewan is a community-based, parent-led provincial organization. Originally started about 20 years ago by a group of parents of children with FASD with the goal of providing information to others in their situation, it has expanded considerably since then, and now employs eight paid staff members. In 2011-12, the Network established a Family Support Program with funding from the CDS, which provides individualized need-based support to individuals and families in Saskatoon who are living with FASD (suspected or diagnosed), as well as monthly group meetings for caregivers. The program currently employs three family support workers.

The main intent of this program is to help individuals and families navigating multiple systems to receive appropriate services and support while increasing their practical knowledge about living with FASD and how to support someone living with FASD. Depending on the family's needs, support workers may help them access diagnosis and assessment, mental health care, counseling, addictions, and/or mentoring services; advocate for them with the school and legal systems; behavioural consultation and intervention identification; and assist them in obtaining employment or income support and/or funding from other sources, including CDS. The support workers are also involved in other activities such as the Mental Health Strategy, Caregiver Workshop, Parent Retreat, Sibling Retreat, and a variety of informational sessions to spread awareness about FASD throughout the province.

Regina Community Clinic

Founded in 1962, Regina Community Clinic is a health care cooperative providing primary health care. The clinic began offering FASD programming in 2004, and in 2005 established the FASD Centre, which provides diagnosis and assessment services. In 2010, a series of community-based meetings identified a significant gap in services for individuals with FASD; in response to this, and building on their previous experience providing services to these individuals, the Clinic obtained funding from the Regina Qu'Appelle Health Region to establish a Life Skills and Addictions Program for individuals over the age of 16 with suspected or diagnosed FASD, beginning in mid-2011. At the time of this evaluation, the program employed two full-time staff, referred to as 'coaches,' as well as funding part of the program director's time.

The program is targeted at hard-to-reach youth and adults, and provides community-based support, counselling, and intervention services. Coaches work with clients on issues such as personal hygiene, pro-social behaviors and self-regulation, self-esteem, personal safety, housekeeping, cooking, grocery shopping, addictions (including street drugs or gambling, etc.) and alcohol-related issues. Three weekly group programs are offered: a men's group, a women's group, and an addictions and recovery group. Outings to community events and amenities are also organized. Clients may also access the other services provided by the clinic that include nutrition counselling and exercise facilities.

3.0 Methods ¹

Program evaluation is "the systematic collection of information about the activities, characteristics and outcomes of programs to make judgments of the program, improve program effectiveness and/or inform decisions about future programming" (Patton, 2002). Evaluations identify gaps in programming, address strengths and weaknesses and increase opportunities for program strengthening and sustainability. This evaluation used a qualitative approach, conducting semi-structured focus groups and interviews.

Focus groups were a fast and efficient way to gather information from program staff (i.e., mentors, coaches or family support workers at each of the four community-based organizations and the CDCs). The main purpose of focus group research is to draw upon the participants' attitudes, feelings, beliefs and experiences by capitalizing on communication between research participants to produce in-depth information (Gibbs, 1997). Focus groups elicit a multiplicity of views, sharing of experiences, and emotional processes in a group context. Further, the sense of belonging to a group can increase the participants' sense of cohesiveness and help them to feel safe to share information (Onwuegbuzie et al., 2009).

¹ This project was granted ethics approval by the University of Saskatchewan Research Ethics Board.

Individual interviews were conducted with program administrators, clients and partner agencies from each of the four community-based organizations, as well as with service providers and clients from CDS. Compared to focus groups, interviews allow for more in-depth conversation with participants. Interviews are also appropriate for exploring sensitive topics that participants may not want to talk about in a group environment (Gill, 2008). Further as Crabtree et al. (1993) have pointed out, a number of logistic factors such as the mobility of the participants and flexibility of schedules determine which method is more appropriate.

Program administrators were interviewed separately from the staff in order to not create any bias or discomfort to staff when discussing topics related to their employment or role. The roles and capacity of each of the partner agencies and service providers varied greatly, allowing researchers to obtain more detailed, in-depth information through interviews. Finally, clients of these various programs, by definition, have cognitive disabilities that often lead to anxious, agitated or uncomfortable moments in group settings with unfamiliar people.

The focus groups and interviews were both semi-structured, allowing researchers to develop key questions that help define key areas to be explored. This also allowed for the flexibility to ask participants to elaborate on information that may not have been previously thought of by the researchers.

Logic models

Based on materials provided by the four community-based organizations, we drafted logic models for each of the support programs, identifying program inputs, activities, outputs, short-term and long-term goals. We shared these drafts with program managers and solicited feedback on them, then revised them accordingly. We used the logic models to help us understand the programs better and to guide the development of focus group and interview questions.

3.1 Evaluation questions

This qualitative study addressed the following evaluation questions:

1. Program reach

- a. How have the programs been publicized and participants recruited?
- b. What steps have program administrators taken to increase the program utilization by the target population?
- c. What are the barriers to involvement in the program and to increased enrollment?

2. Implementation

- a. *Program delivery*
 - i. How is the program actually being delivered, according to staff and clients?
 - ii. How do frontline workers perceive their caseloads and adequacy of time?

- iii. What kinds of partnerships and collaborations with other agencies are in place?
- iv. What are the strengths of the program?
- v. What challenges do staff face in delivering the program?
- b. *Program Uptake*
 - i. What is the level of interest that the clients express in uptake of the program?
 - ii. What are the challenges faced in client retention?
 - iii. What strategies have proved successful in client attendance and retention?

3. Effectiveness

- a. What impact has the program had on clients (e.g., lifestyle, physical health and living conditions, emotional, social, and spiritual health), based on the perceptions of staff, clients, and partner agencies?

4. Maintenance and improvement

- a. How might the program's effectiveness be increased?
- b. Through what means could individuals with cognitive disabilities be better supported overall?

The program administrators at each of the four community-based organizations were consulted for feedback on the evaluation questions (Appendix A) and methodology and their suggestions incorporated.

3.2 Data collection ²

Cognitive Disabilities Strategy

In October 2013, the 12 CDCs and the coordinator of CDS were invited to participate in a two-hour focus group in Saskatoon (Appendix B.2). All agreed to participate, but three consultants were unable to stay when the time came (which was at the end of a consultants' meeting) (Appendix F.2).

After the focus group, consultants were invited to provide further information via e-mail; three did so.

The consultants were asked to provide contact information for clients and service providers in each of their respective regions. We contacted clients and service providers via e-mail (Appendices B.1 & B.2) or telephone and scheduled interviews with interested participants. It should be noted that not all regions provided contact information for clients and service providers and not all clients and service providers we contacted were interested in participating. Seven client interviews were conducted by phone and one in-person (Appendix F.5). Nine services provider interviews were

² Signed consent was received from all participants in the study (Appendix C) with the exception of four CDS clients, where verbal consent was obtained due to logistics.

conducted by phone, while one service provider provided a written response (Appendix F.6). The length of these interviews ranged from 20 to 60 minutes.

A total of 18 interviews and one focus group were conducted with a total of 31 participants (summarized in Table 1). All participants were given the option of receiving a copy of their transcript for review and making changes if they wished to add or remove any information (Appendices D & E).

Community-based organizations

Between September and December 2013, we recruited participants and collected qualitative data from program administrators, frontline staff (mentors/coaches/family support workers), clients, and representatives of partner agencies.

Program administrators and staff

Program administrators provided us with a list of frontline staff at each of their respective organizations. Letters of invitation were e-mailed to all staff at each of the programs (Appendix B.2). Interested participants were asked to contact the researchers and times and dates for interviews and focus groups were scheduled. All staff and program administrators agreed to participate. Focus group sessions with the frontline staff and interviews with the program administrators were conducted at each of the four community-based organizations (Appendices F.3 & F.1) and audio-recorded. The focus groups ranged in size from two to ten participants and lasted approximately 75 minutes.

Clients

Program administrators and staff at Regina Community Clinic, Aboriginal Family Services and CUMFI were asked to provide us with a list of five to eight potential clients for interviewing. We wanted clients with varying demographics, who had been participants in each of the programs for different lengths of time. The interviewer visited the Regina Community Clinic and Aboriginal Family Services on several occasions, interacting with clients in general, to gain familiarity. Each of the organizations selected five to six clients who met our criteria. Letters of invitation were given to the selected clients by their mentors/coaches (Appendix B.1) and they were verbally asked if they would be interested in participating. All clients, who were approached, were interested in participating (See Table 1 for a detailed breakdown of number of clients by organization). We worked with the program administrators and staff to schedule interviews with interested clients. At each of these organizations, mentors/coaches were invited to be with the client for the duration of the interview to ease anxiety and increase comfort. Near the end of each interview, clients were given the option of asking their mentor/coach to leave the room (Appendix F.4). Nearly all clients requested that he or she stay.

The FASD Family Support Network of Saskatchewan sent a letter of invitation generated by researchers to all families who participate in their Family Support Program (Appendix B.2). Families were told to directly contact us if interested in participating. Two families accepted the invitation and a time and date were scheduled to conduct interviews.

Partner agencies

Each of the four community-based organizations was asked to provide contact information for representatives from three to five partner agencies for interviewing. We wanted partner agencies with varying roles and levels of interaction with each of the programs. The four organizations provided us with three to five potential partner agencies to be interviewed. From the lists provided, we selected various individuals based on their role and contacted them directly via phone and/or e-mail to arrange interview dates and times (Appendix B.2). Not all of the contacted partner agencies were interested in participating or had time to participate. In these instances, the next partner agency on the list provided was contacted. Two partner agency interviews were conducted in person, while the other ten interviews were conducted by phone (Appendix F.6). The length of these interviews ranged from 15 to 30 minutes.

As Table 1 shows, a total of 35 interviews and four focus groups were conducted with a total of 51 participants at the four community-based organizations. All participants were given the option of receiving a copy of their transcript for review and making changes if they wished to add or remove any information (Appendices D & E).

Although we attempted to interview a diverse range of clients, high/complex-needs clients were underrepresented. These individuals are characteristically difficult to contact or meet with, are highly transient, do not have phones or addresses and find it difficult to keep a schedule or remember appointments. Further, due to the nature of their disability, many clients were agitated and anxious during the interview and were unable to provide clear, in-depth answers. For this reason, the reliability and validity of their responses may be questionable.

Table 1: Interview and focus group participants of the four community-based organizations and the Cognitive Disabilities Strategy

Program	Participant groups	# participants
Aboriginal Family Services Mentoring Program	Program administrator interview	1
	Mentors focus group	3
	Client interviews	5
	Partner agency interviews	3
	Total number of participants	12
CUMFI Wellness Centre Mentoring Program	Program administrator interview	1
	Staff focus group	7
	Client interviews	6
	Partner agency interviews	3
	Total number of participants	17
FASD Support Network of Saskatchewan Family Support Program	Program administrator interview	1
	Family support workers focus group	3
	Client interviews	3 (2 interviews)
	Partner agency interviews	3
	Total number of participants	10
Regina Community Clinic Life Skills and Addictions Program	Program administrator interview	1
	Coaches focus group	2
	Client interviews	6
	Partner agency interviews	3
	Total number of participants	12
Cognitive Disabilities Strategy	Consultants focus group	10
	Client interviews	10 (8 interviews)
	Service provider interviews	11 (10 interviews)
	Total number of participants	31

3.3 Data analysis

All interviews and focus groups were audio-recorded and transcribed verbatim. The transcripts were then analyzed by grouping responses under the appropriate evaluation question, organizing and summarizing the responses, and selecting illustrative quotations.

4.0 Findings

In this section, we present the findings from the interviews and focus groups, separately for each program.

4.1 Cognitive Disabilities Strategy

The evaluation of the CDS focused on the services provided by the CDCs and CDS funding for which individuals with cognitive disabilities may apply if they have unmet needs and meet the program's other criteria.

4.1.1 Evaluation participants

The program coordinator for the CDS had only been in his position for six months at the time of the focus group. With the exception of two consultants who work half-time, all consultants are employed full-time. Both Saskatoon Health Region and Regina Qu'Appelle Health Region employ two consultants; in other areas, one consultant is responsible for one or two health regions. Their host agencies are diverse, including school divisions, health regions, and community-based organizations. The consultants had been employed with CDS from six months to five years. All consultants are experienced and possess university degrees.

We interviewed eleven service providers: two individuals who provide mentorship services to several CDS clients; a therapeutic horseback riding service provider; two social workers at the Alvin Buckwold Child Development program who have served as team leads for CDS for several years; the Executive Director at the Community Living Association of Saskatchewan; a supervisor for front-line case workers at Community Living Service Delivery; a program coordinator for a non-profit organization working with people with disabilities; a coordinator for a youth program at Radius Community Centre; an individual who works with youth with acquired brain injuries at Radius Community Centre and serves as a team lead for CDS; and the Employment, Education, and Transitions Facilitator at the Saskatchewan Association for Community Living. All are based in Regina or Saskatoon, except for one who works in a small city about 100 km outside Saskatoon.

We also interviewed eight families receiving support from CDS: the mother of a young daughter with a genetic disorder; a female in her forties suffering from a stroke; three families who each have a child diagnosed with autism; the grandmother of a boy with 'special needs'; and a mother

and her two children who all have a cognitive disability. Six of these families live in rural areas of Saskatchewan, and two live in urban areas.

4.1.2 Program delivery

The foundation of CDS is the collaboration between clients, consultants and service providers. The role of the consultant differs across regions. Most consultants reported spending close to 50% of their time on administration. The range of duties performed by consultants is evident from clients' responses; they include providing information about services and programs, emotional support, and help applying for CDS funding. In rural areas, consultants often take on the role of a mentor and provide one-on-one support to clients as expressed by this client, "She'll come with me to certain appointments, and that is a huge, huge help."

Due to the vast geographical regions that most consultants cover, clients often do not meet with their consultant but communicate with them via telephone or e-mail. Most clients found communicating by telephone or e-mail the most effective. One client, whose consultant lives two hours away, would meet up with her consultant once a month and talks with her on the phone at least once a week. As another client said, "She's very available to me by phone, and by e-mail, and she's very, very quick to reply." Another client noted, "She's very good with the e-mail . . . I've never met her in person."

The frequency of contact with consultants depends upon the need of the client. As one client explained, "I would say every couple months. It was more, in the beginning, when she was learning our case. But now it's just whenever needed." However, a number of clients recognized that their consultants were being spread too thin, "Because they end up being so overloaded that we don't...until renewal time, you don't hear from them." Another client who fills out her own applications explained, "I tell her which forms I need, and she makes sure that I have it. I know for other families she does meet with them and helps them fill it out, and getting the forms all together for them. I know with filling out the paperwork, our first few years, she had tried, she came to some meetings, but just being so overworked . . . [there's] not quite enough staffing."

Similarly, service providers provide a range of support services to clients. In particular, clients noted the help they receive with filling out and submitting their application forms, "Because [the application is] so specific, and you have to use it for specific things, and figuring that all out and so [worker at ABI] helped us out with that. She pretty much did the application." Another client noted the role her autism consultant played in submitting the paperwork for CDS: "Actually, what happens is my autism consultant within the health region is the one who has been the biggest help to me. She does everything [with regard to CDS application]."

4.1.3 Program reach

Publicizing the program: Service providers play a vital role in spreading the word about the Strategy when they see it may be a good fit, “We let people know about this program, if they’re looking for additional funding of some sort or if they’re, and saying, there’s this program, Cognitive Disabilities Strategy, and it’s where you get funding for individuals who fall out of the realm of whatever.” CLSD staff often recommend CDS when they have clients who are above CLSD’s mandate but still need support and have a cognitive disability. Clients confirmed this as they reported hearing about CDS through service provider agencies and systems (i.e., Social Services, schools, etc.). Consultants often publicize CDS through local committees that they serve on.

Consultants suggested that this program could be publicized using public awareness commercials on television; using media online, such as YouTube ads or updating the Ministry of Health website to include the CDS application and guide; and through in-person presentations.

Barriers to involvement: Consultants, clients and service providers identified several reasons people with cognitive disabilities may not get involved with CDS. Many service providers cited lack of awareness of the CDS as a barrier to involvement. One of the mentors has recommended CDS to several people and believes there are “tons of people out there that would be fit for this. I think they’re just not aware of it.” Similarly, a consultant feels that “there are a lot of people out there who could access CDS or need to access CDS or could benefit from it that don’t know about CDS. That’s huge.” A client expressed how long it took before she became aware of CDS: “Oh, my goodness. We went through years with dealing with everything on our own . . . we were trying to find out who was out there that could help us. It was ‘knocking on doors’ kind of thing, and we weren’t getting anywhere.”

A consultant mentioned that those living in rural areas are less likely to know about CDS than those living in urban areas. She plans to increase awareness in rural communities by working with public health nurses and visiting rural schools. As a client mentioned, it isn’t just a lack of awareness about CDS but also the accessibility of CDS and related services and supports since she lives in a rural area, “I was kind of just Googling all of our options as far as different services available to a family that has special needs and I came across the Cognitive Disabilities Strategy on one of the government websites . . . it wasn’t until this year that they hired somebody locally that we were re-introduced to the program.” Some service providers find that schools and other service providers don’t mention CDS as a source of funding: “It is our impression that certain schools, individuals, professionals, etc. tend to shy away from the CDS process, which further leads to the inequity of services depending on ‘who’ families are connected with.”

Insufficient understanding and openness around cognitive disabilities can also prevent people from accessing CDS. One consultant explained: “FASD is still a subject that has limited awareness in both the professional and public realm here.” The stigma associated with cognitive disabilities is a related barrier. As a mentor noted, “people do not want to admit they have a disability or need help.”

Another service provider felt that parents often feel “that their child doesn’t fall into that category, or they feel that their child is too high-functioning.”

A consultant explained that the CDS works better for some clients than others: “CDS is really ideal for an individual that has family and community supports in place already. The FASD population is a population we really struggle to support. They’re often the ones that we end up trying to case lead for because they’re so disconnected and so much transiency going on. . . They need something much more flexible than what we can provide.”

Some aspects of CDS itself may get in the way of people accessing it. A consultant mentioned that CDS is perceived as a very disorganized strategy. Some service providers and consultants identified the application to CDS as a barrier to involvement: “I think our application (the one we just revised) is much too complicated and that this makes the service even less accessible to people.” One service provider finds that CDS is very specific around the paperwork that needs to be submitted before clients can get funding. As one service provider said, “I think it might be the process to get an application in, and if they’re not attached to us . . . like obviously it’s based on income and based on the Daily Living Support Assessment, so finding someone to do that . . . can be a bit of a barrier of people accessing.”

The amount of funding a family qualifies for from CDS is dependent upon the income of the family. Service providers noted this as a barrier for many parents accessing funds for their children: “I think a lot of the families don’t qualify based on income level, which is . . . always challenging. . . I know that there are families who are just making ends meet, who aren’t able to qualify for funding because their income is too high. So I think the biggest barrier is income level.”

4.1.4 Strengths

Knowledgeable, supportive consultants: A major strength of CDS identified by clients are the consultants. Many clients were appreciative of the support they provided. They generally felt that they had good communication with their consultants whether by phone or e-mail, recognizing that meeting in person is usually impractical, given the large area the consultants (in non-urban regions) are responsible for. As one parent said, “She’s really good, she answers your questions quickly; if she can’t answer them herself, she finds the answers and gets back to you very quickly.”

Another parent shared similar thoughts about the impact her consultant has had on her and her family, “With [our consultant] we found her to be very helpful, very knowledgeable . . . out of the whole process, everything that we’ve been through, [our consultant] has been the most helpful and most wonderful young lady that we’ve dealt with.” Service providers also echoed similar sentiments and appreciate the support from their local consultants. One mentor thinks the two consultants he’s had the opportunity of working with are wonderful and are always willing to listen and offer knowledge, “Working with CDS [consultants] . . . has been great, communication and coordination of services are the best.”

Despite the lack of clear guidelines regarding the roles of a consultant [see 'Challenges'], they function as a strong team and take on responsibilities. As one consultant mentioned, "We don't say no and we all care. We all seriously care about every single person that's on the end of our line. How many of us are taking our personal calls or taking calls from clients...we go on holidays but we don't turn off our phones because we know we're it." This consultant went on to explain that they don't turn clients away and say, "That doesn't meet our mandate. We can't help you."

The coordinator of CDS praised the commitment the consultants have for their jobs and noted that this is the strongest team that he's ever been a part of. One consultant said, "When things get tough you could either turn on each other or you could be a stronger team. We're a stronger team."

Working intersectorally: Consultants placed great emphasis on being able to work across human service sectors. This allows them to communicate and collaborate with various agencies and levels of government. As one client expressed, "I think the strength is that we are able to move in between and across other agencies, I believe the benefits from consultation, team planning are strengths." Another consultant agreed with this and stated that working as part of an intersectoral team she "can go to school, to home, to different people and kind of cross all those boundaries that some people can't."

Meeting unmet needs: Consultants, clients and service providers placed great value on the funding that CDS provides. As a result of this funding, families are now able to meet unmet needs, just as intended. As one consultant expressed, "The main strength is the fact that CDS is a framework to support individuals with cognitive disabilities. Unmet needs of these individuals can therefore be met through CDS." (See 'Program Impact' for more on this.)

4.1.5 Challenges

Delays in processing applications and claims: The most frequent complaint we heard had to do with the complexity and length of time required to apply to CDS for funding and receive approval and payment. First, one service provider mentioned that it can take several months for the results of funding decisions to be shared with applicants, which creates anxiety as clients wait to hear whether they will receive funding. The length of time it takes to approve mentorship funding can exacerbate the already difficult process of finding a mentor. One service provider gave the example of submitting an application for a mentor for a child in May, with the intention of the mentor being able to work with the child over the summer. However, nothing was heard until the parent and team lead inquired, and finally, in October, the mentor was approved. "In the meantime, the team lost the potential mentor that they had in mind to hire and had to start the hiring process for a mentor all over again. This process has taken another month, and the mentor likely will not start until January."

Second, over half of the service providers we interviewed mentioned delays in mentors being paid as a significant challenge. As one service provider explained: “It’s already a huge challenge for us to find people who are qualified service providers, and then people don’t really appreciate when they’re not paid on time.”

The payment process seems unnecessarily slow and complicated even when everything is done properly, but on top of this, there are times when communications go astray, CDS staff are on holidays or sick, etc., and payments are delayed even longer. Mentors complain to the service providers they are working with, who then have to look into the problem. A service provider explained: “If one of our [mentors] has submitted an invoice, and they haven’t been paid for a reasonable amount of time, we do follow up, we contact their team lead and we contact CDS intake workers, and we talk to them about why this person hasn’t been paid, or what the holdup is. And that has happened a few times in the past, especially these past few months, where a form or invoice just kind of got lost out there into space, or they weren’t processed properly, or something where there’s been miscommunication, where it’s been like eight weeks or more between somebody submitting an invoice and actually getting paid . . . I wouldn’t want to work at a place that it takes eight weeks to get paid.” A mentor stated that she received payment anywhere from 3 to 21 days after invoicing, and knew of mentors who had gone up to three months without being paid. A client wondered why claims could only be submitted once a month, as that contributes to a longer lag time in mentors getting paid.

Two other clients shared stories that illustrate these problems. The first submitted a request for funding for medical travel, which went back and forth between their regional base and Regina for two months, with no decision being made. In this client’s opinion, “nobody seems to know what they’re doing any more . . . the system . . . is not functioning properly.” The second described having to “go through quite some rigmarole to get that money.” In the spring, they submitted their information as they had done in previous years, and after a couple of months were told that the forms had not been received, even though the consultant had proof of it being faxed. As a result of this, the funding (which was supposed to be for the summer) was not received until the fall.

As this client explained, breakdowns in communication like this are frustrating and add to the stress they experience as parents of a disabled child: “I know it’s a little bit of money, but that little bit of money counts. That helps us when we need to hire someone. It was very frustrating as a parent, because . . . I have enough to worry about. I don’t need to be phoning and finding out what’s going on.” This person indicated that this problem had not happened before and that it might have been due to turnover in CDS staff.

Obtaining a DLSA score through the Saskatchewan Abilities Council (SAC), a necessary step for CDS funding, can also slow down the process, as one consultant mentioned this can take six to eight months. However, this person also commented that “communication with the SAC has improved significantly over the last few months.”

One of the service providers who complained about delays in mentors being paid, as well as a mentor mentioned changes that are being made to the CDS payment system that they hope will improve its timeliness. Moreover, the delays are not universal, according to another service provider: “Some of [the mentors] haven’t had any issues at all—it’s been really easy and they’ve gotten paid on time. And then other ones have had problem after problem.”

Application and renewal processes: Many of those we interviewed cited the application process as a challenge, describing it as time-consuming, complicated and onerous. Consultants noted that each region has a different application process, although there is a move towards standardization.

One client commented that filling out the application is “really long and tiresome, to be honest, and kind of degrading to a lot of parents” because it requires them to focus on their child’s “worst day” rather than on the gains that have been made. This person pointed out that in some cases, after filling out all the paperwork, getting a DLSA, having an interview, talking to psychologists, getting all of one’s therapists to write letters, etc. the applicant might turn out to be just above the income cut-off and not receive any funding.

A service provider mentioned that the CDS paperwork for CDS takes up a lot of staff time, because in many cases they are the team lead: “Since CDS has come along, it’s really increased workload and paperwork to get it done and keep it together and filling out the applications and making sure we’re doing it right. So it’s pretty intensive.” Another service provider described the application process as “a bit challenging.” This person has found that it’s difficult to get teachers involved in the application, as CDS would like, because they don’t have the time and energy to fill out all the forms, and they find it hard to identify gaps that are outside of school.

In many cases, families write their own applications without much assistance, and according to a service provider, they find it challenging to know how to word things so that the needs and ways of meeting those needs will be seen as legitimate and appropriate by the committee. This person explained that sometimes employees in her agency serve as team leads, but that can be difficult because they “don’t necessarily work closely enough with the families for us to take on the team lead. And we don’t get paid for it. And so we’re already pretty maxed out with all the kids that we have.”

This is compounded by apparent inconsistencies in what will be funded from year to year. Some families have had funding for a mentor, but the next year, they apply for the same thing and are turned down, according to one service provider. A client questioned this also, wondering why some of his expenses are covered sometimes but not other times. Another client claimed that there are inconsistencies among the CDS regions in terms of what is covered.

Related to this is uncertainty about what are eligible expenses, according to one service provider, who works with families to help them identify services or needs to apply for CDS funding for: “Sometimes families . . . will see a want and they perceive it as a need, and it can create conflict

where we have to be the ones that say, 'No, we're not going forward with this, we don't believe it's an unmet need,' and so I think there's not enough parameters about what to apply for with CDS. [We need] a little bit more detail as to exactly what you can apply for . . . because families are told that you can apply for anything."

One of the service providers found the renewal process also onerous, and unnecessarily so. She commented that while she believes it's important to request information from parents and service providers to document the child's progress and make a reassessment, parents often complain that it feels "a bit redundant." She ends up writing "a lot of these letters," often at the last minute (which may be the result of parents putting it off). A client felt that if they are applying for the same things every year, they shouldn't have to go through such an elaborate renewal process, which takes up not only parents' time but also CDS staff's. This client also mentioned the expense associated with adding new services: "Anything we want to add to it, we have to contact [CDS] and say, 'Okay, I would like to do this, can we add it in to the renewal?' Then you have to fill out another formal request, get letters from a therapist, which every letter costs you about \$90, and that part's not covered through CDS funding."

Funding limitations: Four of the clients we interviewed felt that the funding they received through CDS was insufficient for their needs. One explained, "You're allowed so much per year, and then you divvy that up into the months, and it's just lots of times there might be more month than there is money. So once the money for the month is run out, then the activities, the extra help stops." In particular, a couple of clients mentioned the challenge of hiring a qualified mentor and paying them adequately from the CDS funding they receive. Finally, a client who lives some distance out of the city commented that because the mileage he has to pay for workers to drive out to his home comes out of the funding, his family has less funding left for the actual service than someone who lives in the city.

Related to this are restrictions on what funding can be used for. A client and a couple of service providers mentioned that a limitation of the CDS funding is that it can only be used for disability-specific programming, even in situations where other kinds of services or programs would be very helpful to the client. One of the service providers explained that "if we have a youth who wants to swimming, for example, they can get funding to cover a swimming program if it's through autism services, but if their mentor wants to get them a leisure pass so that they can work on swimming on their own, that's not covered, because it's not disability-specific." The service providers mentioned that parents often express frustration at these kinds of restrictions. The client who brought this up is caring for his wife who has an ABI. He explained that since his wife became disabled, he has to "take care of the family, do all the cooking, do everything that a household does, including cleaning and taking care of things." They applied for CDS funding to hire a house cleaner but were turned down because, they were told, "that doesn't affect [your wife]." He would like it if CDS could "have a look at the family as a whole and what are their needs to help this transition, and to help the whole family function better."

Lack of role clarity: The roles and responsibilities of the various team members, organizations, and service providers, including the consultants, are often unclear, and there are some problems in how they work together.

One service provider explained that people at their organization end up helping with hiring and supervising mentors, even though this is not supposed to be their responsibility, but there is no one else to do it. “I try to do as little as possible because I’m really not supposed to be doing anything, but if I don’t, CDS is not going to work.” From connecting people who would like to be mentors with families who need mentors, assisting families with the interview and hiring process, to supporting mentors and trouble-shooting when payment delays occur, this person estimates spending about a day a week on CDS work, which is outside her job description.

Consultants in particular expressed dissatisfaction with the lack of clarity and inconsistency around their roles. One said, “There was a clear definition of a consultant but that has changed through the years. We have a lot of consultants who are actually case leads as well in applications.” Another disagreed, saying “[The consultant’s role] didn’t change through the years. It never was what was defined. So in reality the consultant role never was what it is on paper.”

Nearly all consultants feel that they are doing too much administration, which prevents them from properly carrying out their role. Many feel they have to ‘do it all’ because there is no one else to do it, similar to the service provider described above: “Some [consultants] are out there providing everything. They have to because they’re the only people in their region for CDS and they don’t have anyone else to support them.”

The complexity of CDS is seen as contributing to this lack of clarity, as one consultant explained: “CDS is a difficult strategy to explain, let alone understand. CDS consultants need more direction (expectations and limitations) in their mandate, policy and procedures.” Others commented that “all these ministries, they’re a part of it but don’t really want to be part of it” and “Nobody wants to own it.”

Need for more and clearer communication: One area that relates to a number of the challenges mentioned is communication, as several people commented that better communication about the whole process (e.g., how to apply, what expenses are covered, mentorship requirements, timeframe for approval) would be very helpful. A mentor specifically mentioned wanting clearer guidelines for this role.

Finding mentors: The difficulty of finding mentors was mentioned by a service provider and a couple of consultants. The service provider, who works in a rural area, says it is a particular problem there. They often get applicants from outside Canada but are unable to bring them in, and are also concerned about the qualifications of the people who apply: “My clients have lots of challenging

behaviors, and it would be best if [mentors] have experience.” It is especially hard to find qualified male mentors.

One of the consultants said that they are in the process of setting up a mentorship program with a coordinator to hire, train, pay and monitor mentors, but “until this is put into place, families are on their own in terms of finding someone as it is not the job of the consultant to provide this service.” The other consultant agreed that it is hard for families to find appropriate mentors without a community run mentorship program.

Not enough consultants: Each of the consultants has a large geographic region to cover—three of the consultants have two health regions each, and two regions have a half-time consultant; only in Regina and Saskatoon is there more than one consultant per health region. This makes it very difficult for consultants to provide effective and timely service to all the clients in their region. Clients in the southern part of the province explained that their CDS consultant is based in a city over three hours away from where they live, and in the two years they’ve been working with her, they had never seen her. They commented: “To become more actively involved with this CDS program, it would be better to have a closer accessibility and that [consultants] would be able to make it to team meetings, to understand what is happening in the school, and what is happening in the community.”

4.1.6 Program impact

In spite of the many challenges identified, clients, consultants, and service providers in general spoke positively about the impact CDS has had on clients’ lives. Many commented that CDS funding “fills a gap,” as it was intended to, and wondered where clients would be without it, as this consultant expressed it: “Where would half these people be without the funds that they get or the mentors or the [Speech and Language Pathologists] or whatever? Who would they go to? So I do really feel that we do hit a gap.”

Similarly, a mentor said, “Honestly, I don’t think a lot of adult people would be able to function without it, to put it very simply. Just looking over the history of some of my clients, especially one in particular, he’s sort of borderline, doesn’t qualify for things that he needs that would benefit him, so if it wasn’t for the strategy, for someone being there, involved with him, he would be very lost. . . . I give it 100% thumbs up.”

Another mentor elaborated: “Clients really like CDS supports. We are there to fill a gap, no pressures, clients feel more in control of their lives as they are part of decision making.” An employee of an organization in a more rural area stated, “Without it, I really don’t know where many of my clients would be. They talk about phasing it out, and that right now would be a huge concern for me, just because out here there are a lot of limits. . . . But yes, absolutely, I don’t know what we’d do without it. It’s awesome.”

One way CDS helps families is through the support, advice, and advocacy the consultant provides. One consultant explained that “Families phone me because they feel like they don’t have anybody else to call.” She went on to say that often when a client has been waiting for months to get an appointment or hear back from an agency, she is able to phone the agency and “magically they get an appointment. So just having that person to advocate for them [makes a difference].” A client who has little formal education commented on how helpful it has been to have both the consultant and her son’s mentor to explain things to her and help her understand her son better. Another client who cares for her grandson said, “We actually have somebody that is listening and understanding what we’re talking about.” Another client said her consultant has “helped us with just any little thing that you can think of. She’s just been a good support.”

Many of those we interviewed emphasized in general terms the importance of the funding that CDS provides, and what it enables clients to do that they would not otherwise have been able to afford. One consultant explained: “I think the funding piece . . . is really critical because that’s a huge part of how come this success is happening is because families are able to access funding and then therefore get some of these services in place, whether it’s a mentor or a respite provider, even the stress relief from having travel for medical paid for. Those are huge contributions to success.”

The service provider who works in a smaller community commented that “because we’re in a rural area, where we don’t have many of those things [services], and also just because there are so many clients who are low income, and they don’t have the money to be paying for therapies, or extra respite, or mentorship and things like that, and that can be very expensive. So definitely that is a huge support and makes it a big difference in my clients’ lives.”

Another consultant said that not only does the program have a large impact on individuals and families who receive CDS funding and can therefore access additional supports, it can also “reduce pressure and stress on other agencies to provide services that they are not capable of in order to meet unmet needs.”

Many of those we interviewed gave detailed descriptions of the ways in which CDS funding and the additional support it enables clients to obtain have increased their quality of life. Consultants gave examples of a woman whose children had been apprehended but now with a mentor in place, was able to care for her subsequent children successfully; young offenders who are staying out of jail; clients who have complex medical needs and are now receiving better care; and individuals being able to live independently, stay in their homes or schools, or maintain employment. A service provider described a client with Asperger’s who has been able to live on his own with help through CDS funding with life skills like budgeting and grocery shopping. Another service provider talked about a client who had been in the correctional system, did not have stable housing, and because he didn’t have anything to do during the day, “he would just get himself into trouble.” Now, with a mentor to provide daily support, “he is just doing fantastic now, and I think that’s one of the biggest

successes that the CDS funding has had.” A client described how the consultant, mentor, and home care provider all help her daughter monitor and manage her chronic illness. Both her children have mentors who take them out and show them how to shop, use the library, and so on—“how to just be an adult”—as well as helping with personal hygiene routines.

Support can also facilitate community inclusion and participation in a wider range of activities, as explained by a consultant who commented on “the happiness and the joy on [a client’s] face because they get to go out with some friends or they can go to a movie or do things like that where they couldn’t before.” A woman whose son has autism explained, “Before, my son was always at home in the room watching TV. He’s not involved with other kids because the other kids will laugh at him because of the way he is,” but now, with a mentor, he is able to go out and do more things, like going to the beach, on picnics, and picking berries.

CDS funding helps clients access beneficial therapies that their families would otherwise not be able to afford, including horseback riding, speech and language, art, music, and occupational therapy. It also enables clients who would have difficulty participating in regular sports programs to access special programs for those with disabilities, “instead of having the people heckling on the side wondering why this kid can’t do this, or understand.” The mother of a boy with autism explained that the speech therapy that CDS funding enabled her to pay for has helped her son go “from being completely non-verbal to actually having like a vocal vocabulary of around 80 words.”

Some families use CDS funds to purchase supplies and equipment, such as ear plugs, diapers, and special furniture, as well as dietary supplements, enabling clients to function better and more comfortably in their homes.

Another way the funding helps is by providing respite for family caregivers. One service provider explained: “I have quite a few people who are receiving mentorship from other individuals, so they’re actually getting a chance to spend time with other people than their parents, and the parents are getting a chance to take a step back from their children.” Another described a couple with two adult children who have disabilities, who had not been able to go out socially or travel together because one of them always had to be with their children, but now, with CDS funding to hire a caregiver, they had been able to attend a Christmas party together. A man whose wife has an ABI is able to go to work and sometimes go out in the evening because of the home care that CDS funds; without this support, his wife would be on her own, and would have nothing to do.

Several of the clients we interviewed use CDS funding to hire family members as mentors, which they see as beneficial, as one parent explained: “I think it’s good that CDS is allowed to pay the siblings to do things with [son], because it only doesn’t help the siblings with a little bit of funding, it also keeps the family united, and they do things that keeps the love in the family.” Others

commented that the funding they use to pay someone to provide respite care helps that person as well.

4.1.7 Increasing program effectiveness

Those we interviewed identified several ways in which they believe CDS could be improved.

Update income parameters needed to qualify for support: Since the inception of CDS in 2005, the income parameters that families need to meet in order to qualify for funding have not been reviewed. Many service providers and clients identified this as a barrier to accessing CDS (see 'Barriers to involvement'). Further, consultants and clients argued that income parameters and the amount of funding issued need to be updated. The program coordinator expressed his concerns regarding this: "The funding hasn't been reviewed since implementation. Cost of living has increased but the funding for CDS hasn't been reviewed since." One client, who only accesses funding from CDS during the summer months when her daughter is not in school, expressed similar frustrations: "Because of the funding and how it is rated on income-based, we have a really tough time as we don't access much. I wish they would revamp that part of it, because what's happening now is wages are going up, food's going up, everything else is going up, but . . . the income . . . it never moves up, that bracket. That is one of one of my biggest complaints is that everything goes up, but that never goes up and that's a big challenge for me, because, I'm like, the more income you make, the more it hurts us."

Provide more support for adults: Many consultants and clients addressed the need for community-level support for adults. In many communities, children are well supported with a wide array of services available. As one consultant noted, "In Regina there's a big difference in terms of services offered to kids just because they can be connected to Child and Youth. Autism services, they've got a really strong connection with the school versus our adults particularly once they turn 18 or 22 and are leaving school and then [there's] very little in terms of transition planning. Especially if they're not connected to CLSD and they're used to intensive services and there's just not enough funding available to support those people." Another consultant expressed similar concerns: "So zero to five in my region ... lots of resources, lots of programs out there. . . . Then they hit school and they're kind of like, 'Okay now it's Education's problem,' and then once they're out of school it's like, 'Fly.' There's nothing." This consultant went on to explain that the team support that is imperative after leaving school is minimal to non-existent. A parent who accesses CDS for her daughter shared the same concern about the lack community-level supports available for older children: "She's going to be 13, and we do run out of child care, period. So [my consultant] and I have been talking off and on, because we don't know what is going to happen now, because I used to use a day care before and after school, and now I don't know what we're going to do."

This highlights the need for more services for adults with cognitive disabilities. As one consultant explained, "There has to be a different service delivery for adults. I think [CDS] works really well

with kids . . . I think that we need a program for adults. We need somewhere where they fit in within a system or create a place that they fit in within a system to provide regular consistent service.” Another consultant indicated where adult clients who are not supported by the community end up: “The only real system for adults in our community and probably some of the other ones . . . is Corrections. You don’t necessarily want them involved in that system but that’s the only [system].” Further, one consultant identified that the basic needs of many adults with cognitive disabilities are not being met. “We . . . need to meet basic needs and CDS is a level above basic needs. So until basic needs are met it’s hard in our region.”

Enhance services in rural areas: Clients living in rural areas mentioned the need for more community-level supports. As one client explained, “Unfortunately . . . just being in [a rural area], they don’t actually have a whole lot of respite services available.” Another client who lives just outside of an urban centre explained their location restricts his wife’s access to programs and supports: “There would be a lot more options if we lived in the city and then we would just arrange, like every Tuesday afternoon at one o’clock, the public transit’s coming to get her, and take her to a program. And I think early on . . . we learned that there was some, there were some restrictions because we lived out here.” He went on to explain that because there is no public transportation available, he has to take time off work to drive his wife into the city to take part in programming.

More collaboration between community organizations could strengthen the support that is available in rural areas. As one consultant explained, “I would like to see us as more of a collaborative disability service in our community where . . . in the smaller regions . . . we were part of a team with the ASD workers. We could look at the behavioural stuff together, who’s got the skill set there. Your expertise is in that area, mine is in this area. Let’s divide and send it over that way so that we’re not islands. Because I very much feel like I’m an island on CDS, they’re an island on the Autism Strategy.”

Standardize CDS across regions: One of the most heard complaints from clients, consultants and service providers across the province is the inconsistency of CDS across regions. Consultants are based in various host agencies ranging from school divisions and health regions to community-based organizations. As a result, their salary and benefits also differ. Many consultants expressed the need for standardization across the provinces: “It would be great if all areas were somehow involved with the same host agency or were an employee of somewhere.” Another consultant shared similar concerns, “I would like to be considered a government employee and see the strategy become more consistent across the province. I would like us to have one consistent logo and one consistent supervisory agency across the province.” It is important to note CDS is working towards standardization through the introduction of new consistent forms across the province.

Improve transparency in CDS system: Many clients indicated CDS needs more transparency. They believe that knowing how the system works would help alleviate some of the frustrations they

experience around submitting application and renewal forms and receiving funding. As one client explained, “I’m not sure how this committee works, like if it’s like a jury, if everybody disagrees or one person disagrees, it’s not submitted . . . I’d like to know that, the way the committee works.” Another client expressed similar views, “I think information should be sent to families, on . . . the CDS, what is available, how the committee works, who is on the committee, you know, all these things. It’s important for us to be informed as to how this process is working exactly, because we’re kinda told, oh, it’s going to a committee, and they meet once a month, and you don’t know anything. And I think information is the big part.”

4.2 Aboriginal Family Services Centre Adult Mentoring Program

The first of four community-based support programs we report on is operated by the Aboriginal Family Services Centre in Regina’s inner city.

4.2.1 Evaluation participants

The Team Leader has been in her position for almost three years. The three mentors have worked for varying lengths of time: the one female mentor had been there for about 15 months at the time of the interview; one male had worked there for about six months, then left, and had just returned to work that day and the other male has been with the organization since 2001 and the mentoring program since 2007. In terms of partner agencies, we interviewed individuals employed with CLSD in the Ministry of Social Services; Regina Qu’Appelle Health Region’s Four Directions Community Health Centre; and the Acquired Brain Injury Outreach Team.

We interviewed two male and three female clients. The length of time they had been participating in the mentoring program ranged from a year to over five years.

4.2.2 Program delivery

The core of this mentorship program is one-on-one support tailored to clients’ needs. Mentors assist clients with daily life skills such as budgeting, grocery shopping, and transportation, accompany them to appointments (medical, legal aid, probation or court), provide emotional support and crisis intervention, and advocate for them around bigger issues like housing, legal problems, and Child Protection. They seek out opportunities for clients to engage in low-cost recreational activities that help build relationships, develop social skills and promote health. These include working out and playing sports, going for walks, and attending AFSC events, such as the National Aboriginal Day breakfast, family carnivals, and barbeques. Each activity has an identified goal.

Staff explained that mentors often act like the clients’ “external brain,” helping them get to their appointments and then keeping track of what goes on during those appointments, because clients often have trouble remembering.

When asked what they do with their mentor, clients mentioned many of the above activities, as well as simply “going out for coffee and talking.” Mentors help them with “all kinds of things, anything that needs to be done--usually running around paying bills, stuff like that.” The frequency of contact depends on clients’ needs and their appointments, but is generally once or twice a week for an hour or two. Most clients drop in on the spur of the moment, others have scheduled times.

In addition to providing this one-one-one support, staff frequently interact with partner agencies, such as the Ministry of Social Services and government programs such as Saskatchewan Assured Income for Disability (SAID), the Regina Community Clinic’s FASD Centre, and Ranch Ehrlo, referring clients to them, advocating for clients who are using these services, and communicating information about mutual clients.

At the time of the evaluation, the program had 36 clients, with 10 assigned to the female mentor, 18 to the long-term male mentor, and none to the male mentor who had just returned to work; the Team Leader had the remaining 8 clients on her caseload. At one time there were 45 clients, when the program had three female and two male mentors. (By the time this report was being written, the organization had hired another mentor, for a total of four full-time mentors and one full-time Team Leader, and the caseload had been correspondingly increased.) The program is inclusive and about one quarter of clients are non-Aboriginal individuals.

4.2.3 Program reach

Publicizing program: When staff members speak at events, like FASD Awareness Day activities, or network with other agencies, they use the opportunity to publicize the program. New mentors are given a copy of the Street Survival Guide produced by the Health Region and asked to visit all the agencies listed there, both to become aware about the services offered, and to introduce themselves as representatives of the AFSC mentoring program.

Staff have also made efforts to connect with other agencies and organizations, including the Friendship Centre and the Indian Métis Christian Fellowship, to inform them about the program. The Team Leader is involved in several key groups dealing with people who had cognitive disabilities, including the CDS Intake Table, the CDS Steering Committee, the Regina FASD Network, and the FASD Support Network of Saskatchewan; she explained, “my consistent presence and collaboration has definitely, I think, built a lot of trust in the community whereas before it wasn’t so much.”

Clients hear about program through advertisement (e.g., the AFSC’s monthly newsletter that goes out to the community) and word of mouth; the program receives many self-referrals. As one staff member explained, “A lot of [the clients] know a lot of people affected with FASD and they say, ‘Come into this program. Let’s just check it out. You know, it’s good.’” The location of the AFSC in the North Central neighbourhood of Regina is convenient for many in the target population.

Managing caseload: The program is based upon a weighted capacity caseload that takes into account cases' complexity. It can be difficult at intake to know how to assign clients and what the ideal number of clients per mentor is, because their needs can change rapidly, but 8 to 10 clients was estimated to be optimal. Efforts are made to distribute female clients with children across mentors, as they require more time. Staff reported that some clients require a couple of hours a week, some a couple of hours a day.

Barriers to involvement: A staff member and one of the partner agency representatives both felt that the stigma associated with FASD gets in the way of some people becoming involved in the program.

Retention: Retention of clients is not seen as a problem by staff; the main reason clients stop coming is because they've moved away. However, some clients are very irregular in their attendance and hard to get hold of. Staff reported that they put a lot of effort into contacting clients if they don't hear from them for a couple of weeks.

4.2.4 Strengths

Providing trustworthy mentors: The central role that the program plays in helping individuals with cognitive disabilities find mentors is seen as very important, as expressed by the partner agency representative who works with ABI clients: "I think that it's a valuable service because it is really tough to find mentors. . . . Unless [a mentor has] worked with our clients or we know them or we know them through a reference, we don't know if they're trustworthy or if they're going to do the job well or not. So the advantage of having an agency that screens the mentors is really helpful because I just presume that if Aboriginal Family Services is recommending somebody then they must know who they are." This individual mentioned that there used to be a system in place in which there was a list of pre-screened mentors and someone who would match clients with mentors, which was very useful.

Creating trusting, caring relationships: The warmth and caring between staff and clients was very evident in our interviews. Staff place great emphasis on gaining clients' trust and building rapport with them, which is why they spend a lot of time socializing with clients. "If the client doesn't trust you, he's not going to see you. . . First of all, build that trust. Take them for a coffee, just go and talk and try not to be invasive... then you can start asking questions and see how you can help and get them to open up." Staff talked about the difficulties their clients have with social interactions, which leads to them being isolated.

A related cornerstone of the program is its focus on clients' needs, whatever those may be, as a staff member explained: "We have an open-door policy. If they're in crisis or if they're in need they can walk in front there and ask for us and if we're available we'll try to attend to their needs." The Team Leader emphasized: "That's something that I always try to focus on in our staff meetings is

that, you know, the only reason why we're here is because of our clients. We wouldn't have these jobs if it wasn't for them, you know, and to keep the focus on them and supporting them."

The caring and respect staff have for their clients was explicitly expressed: "I love the clients. That's probably the number one [part of the work], just because the clients are unique. Everyone's different and they're all enjoyable regardless of the life that they are living." The Team Leader believes that the passion staff members have for their work is one of the program's key strengths: "The passion that we have is really strong. And I'm really proud of the team that I have. I'm really proud that they're here because they have that drive and they know where to go. They're very resourceful and very passionate."

The following exchange between a client and her mentor reveals mutual affection:

Client: "[The AFSC staff] are awesome people."

Mentor: "It's because you're awesome."

Client: "Because you made me awesome."

Mentor: "No, you were awesome before you even came."

Another client, when asked what the best part of the program is, responded: "Seeing [mentor] every time. She's a good listener and I can talk to her about anything that's on my mind or that's bugging me. And she helps me a lot with my supports." All the clients we interviewed said that they liked the program and could suggest no improvements.

The respect for clients is recognized by partner agencies. One representative said, "Every time I've ever had anybody that was with an individual from there, regardless of whether or not they were First Nations, the workers were very respectful and they do care. They do care and to me that's the number one thing . . . they're not there just trying to do their job."

This person commented that one individual who had used the mentoring program extensively especially liked having somewhere he could stop in if he needed to, where there were not expectations of him. The representative explained that some other programs have specific expectations of clients which puts pressure on them, whereas the AFSC "really provided just a mentor, not somebody to tell or show them what to do and what they're not doing right and stuff."

Staff's connections with the community: While there has been some turnover in mentors, the fact that both one of the mentors and the Team Leader have been with the program for several years and have become well known in the community was cited by a partner agency representative and staff as a strength of the program. The Team Leader has noted improvements over the time she's been involved: "When I first started here I didn't realize the lack of presence that we had in Regina. . . The feedback that I've gotten from people at the tables that I sit at is always very positive. And I hear nothing but positive things about the mentors, so I know that it's definitely good, whereas

before there was so much apprehension and there was so much reflections of past supervisors or past mentors and stuff. So I know that it's come a long way."

One partner agency representative said, "They really have good staff. They have staff that are very familiar with the community and know the ins and outs and how to work with those well and to connect with the community. . . . I think [the program is] awesome."

Coping with work stress: The importance of helping mentors cope with the stress of their jobs is recognized and addressed by the organization. The Team Leader acknowledged: "You have to be a certain type of individual to work in this field . . . [and have] compassion, patience, flexibility. You have to have a really strong home foundation and even just within your spirituality and everything you have to take care of yourself." To support mentors, the organization has an open door policy where the mentors can access the Team Leader, Program Manager and Executive Director at any time; talking circles have been integrated into staff meetings as well as one-on-one case management meetings. Team Building activities are also organized periodically, such as a Fall Staff Retreat, Christmas team building activities, and staff events in December and June. The weighted capacity caseload system is also intended to help prevent staff burnout by ensuring each mentor is assigned clients with varying levels of need. Mentors indicated that they feel supported by their organization.

4.2.5 Challenges

The challenges this program faces are varied: some are related to FASD itself, some to the context in which individuals with FASD live, and others to the way the program is funded.

The nature of clients' disabilities: An underlying challenge, common to any program serving individuals with cognitive disabilities, is the nature of the disability itself and the impact it has on individuals' lifestyles. Staff commented that one of the hardest parts of their job is "the consistent struggles" clients have. The apparent lack of progress with some clients can be very frustrating: "I have worked with some of the guys since I started and it's like doing the same thing over and over every week. . . They forget what they learned last week. They just keep on doing the same thing and I get them into something else [but then] they go back. They go back and I teach them all over again."

Another characteristic of clients that gets in the way of helping them is that they are easily influenced by other people who lead them "off track." As a staff member explained, "They know what's right but then when it comes down to it, if somebody comes to them and tries to say different, well, they'll listen to that person. . . Even though they know it's wrong and they shouldn't do it, they still will." Mentors do their best to be positive role models during the time they have with clients, but because of these unhelpful outside influences, "They're right back to square one the next day."

Clients' cognitive problems combined with the instability of their living situations mean that they can be very erratic in their attendance of the program and difficult to contact, as noted above, under "Retention." This creates more work for mentors, who may make many phone calls and even visit places the clients frequent in their attempts to locate them.

In addition to having a cognitive disability, many clients also have addictions, which creates another layer of difficulty for mentors, as a staff member explained: "The limitations the individuals experience are due to addictions. . . . When an individual has an addiction, it makes it difficult to provide services to stabilize or support them."

Staff acknowledged that their work can be very stressful, especially when many clients are experiencing crises at the same time and they become personally involved in clients' lack of improvement. "One of the weaknesses is we do get caught up . . . in our clients' cycles, like it affects us personally. Sometimes we'll have that mentality as to why aren't they changing, like, 'Oh, he's at it again,' but not understanding their cognitive disability, right? Understanding that it's brain-based." (As described above, the organization has implemented a number of measures to support staff, recognizing the stress inherent in their work.)

Funding limitations: Several people we interviewed mentioned that the program is limited by inadequate funding levels. This has several dimensions. One is that the program cannot meet the demand for services, as a partner agency representative explained: "Given the size of the mentoring program and the size of the population that requires it, it's not big enough." Staff agreed: "We need more of us."

Second, salary levels for staff are seen as too low in relation to the work they are doing, which has a negative impact on morale and staff retention: "If [mentors] were compensated properly I know that they would feel . . . valued and appreciated--that it's not just all for nothing, because we . . . work and live in a cycle with our clients, so it's difficult for us." Staff attributed the recent turnover they'd experienced to the inadequacy of mentors' salary to meet the costs of living in Regina.

Third, staff turnover creates stress throughout the program, as a staff member explained: "[Clients] flourish with long-term relationships. When I lose staff I lose clients. . . . Sometimes it takes them a while to build that relationship . . . I find with the population that we come in contact with . . . once they build that trusting, supportive, positive relationship and it's gone, it's devastating to them."

Finally, increased funding would also enable the provision of more services that staff and partner agency representatives believe would be useful, such as expanded work hours and more varied activities.

Inadequate housing: A significant external problem mentioned by several people is the lack of appropriate housing for people with cognitive disabilities. Stable housing would provide many benefits to clients, including making it easier for program staff to keep in touch with them. Staff

explained that some of their clients are homeless and that many landlords don't want to rent to them: "As soon as the landlord sees them, it's right away, 'Oh no, it's gone, it's taken.'" When asked what would help them do their job better, one staff member said, "Find a big apartment building with 30 units. We could have that filled ... like now." A partner agency representative also mentioned housing as a big issue, but was not sure that having a group of people with FASD living in the same building would be the best solution.

On the positive side, staff mentioned one landlord they know who builds duplexes and rents units to their clients; he understands their situation and is very supportive. He trusts clients if they are working with AFSC.

4.2.6 Program impact

In spite of the difficulties in seeing progress in their clients noted earlier, staff members were able to describe some specific examples of positive changes, from small to large. One explained: "I like the little changes that I see in some of the young guys that I work with. There was this one young man . . . we were driving down the street and we were talking and he suddenly said, 'This is the longest conversation I've ever had with anybody.' I felt good." Another described a client she had worked with at her previous job: "She was always homeless, had a very negative lifestyle." When this client came to the AFSC, "She came here homeless; she was being taken advantage of by older men and sexual stuff like that. Within that week I finally found her a place and she was settled in. She stayed stabilized for over a year." However, indicative of the instability of the client population, the staff member added, "And now she's MIA again."

Staff members see housing as one area in which they have made progress with clients. They report that the program has assisted with the stabilization of housing for clients who have experienced consistent homelessness. Working with landlords and advocating for clients has allowed individuals to keep their homes. Mentors have also helped clients find supportive housing with the Salvation Army due to the relationship the program has with this organization. A staff member shared this story: "One of my guys . . . was homeless, transient, [and had] eviction issues. I got him a house, him and his partner. They had done well until, you know, gangs around here just take over places and force the tenants out and they take over. . . . Myself and another employee at Welfare Rights we would go and do home visits and eventually the old gang members there had to leave because we would always be there and interrupt their [activities]."

Co-existing mental health problems create additional challenges for some clients. A staff member singled out the success in stabilizing a client with mental illness through the support and understanding of the mentor. This individual was able to maintain housing, get the arrears paid off, keep the home safe and clean, and maintain personal hygiene with the help of the mentor.

Another way in which mentors have had an impact on clients' lives is by helping them get off probation, as one staff member explained: "[A client] was on probation forever and wouldn't go to

his meetings. But when I got involved with him I would make sure he made those weekly meetings and eventually he is off probation.”

Clients themselves had difficulty articulating how the program had helped them, which likely reflects their disability. For example, one said, “I’ve always made good choices. . . . I don’t have many problems.” Others answered all our questions about program impact affirmatively, but did not elaborate. The mentor of the client who has been involved with the program the longest time explained that through the program, the client has accessed several types of counselling and life skills training and was about to complete a program to be a concrete finisher. His mentor had recently helped him get an apartment. When asked how the program had helped him, the client responded: “More positive thinking and more confidence. . . . I don’t struggle as much. [Mentor]’s there whenever I need it, he’s someone to talk to, someone to tell my problems [to] and gives me positive advice about things.”

4.2.7 Increasing effectiveness

As mentioned under “Challenges,” there was general agreement that the AFSC mentoring program is important and needs to be expanded. A staff member indicated that increasing to six mentors from the current four would be a great help. The partner agency representative working in the area of ABI explained the ongoing need for mentors for their clients: “I’m really hoping that it continues and that there would be more agencies that would provide mentors Either expand what Aboriginal Family Services are doing or have more agencies that would have mentors that would take on that role because it’s sure helpful for us because our [ABI] clients are for the most part living in the community. They live many, many years and they have lots of issues. They may need a mentor forever, not just a temporary thing.”

The Team Leader has several specific ideas for programs she believes would greatly benefit individuals with cognitive disabilities, including a casual labour program in construction, a dedicated court worker, and supported housing or a shelter.

The need for more education on cognitive disabilities in order to reduce the stigma, especially for adults with FASD, and increase access to resources was mentioned by both staff and partner agency representatives.

4.3 CUMFI Wellness Centre

The second community-based program described in this report is run by CUMFI in Saskatoon’s inner city. This mentoring program was started at the same time as that of the AFSC and the two programs are based on the same model.

4.3.1 Evaluation participants

The project coordinator has been in her position since 2007, when the mentoring program was established. We interviewed five mentors; the Mental Health Coordinator and Resource Room Coordinator (whose positions are not funded by CDS) also participated in the mentors' focus group, and some of their comments pertaining to the mentoring program are included here. The mentors have been with the program for 2.5 to 5.5 years, except for one who joined the program a little over a year before the interview. (A sixth mentor, who has training in addictions counselling, was off work for medical reasons at the time of the focus group.) The Mental Health Coordinator has been employed by CUMFI for 18 months and provides support to mentors, as well as counselling clients; the Resource Room Coordinator had been in his position for two months, and oversees the Resource Room, interacting with clients while they are there.

We also interviewed the psychiatrist who has worked with CUMFI to diagnose adult FASD clients for four or five years, and in the past year has been going to CUMFI to consult with clients there; an employee of the Ministry of Social Services, who did not seem to have much contact with the mentoring program; and an employee of the Saskatoon Crisis Intervention Service, which has a caseload of difficult-to-engage, hard to serve clients, three or four of whom are also clients of CUMFI's mentoring program, and which has been involved with the mentoring program from the start.

We interviewed four female and two male clients. The length of time they had been coming to the program ranged from seven years to a few months, with most having been involved for at least a few years.

4.3.2 Program delivery

The mentoring program consists mostly of one-on-one support. Group activities, like going to a movie or corn maze, have sometimes been organized, with mixed success—as staff explained, it's difficult to get clients to show up at a set time and they have very limited funds for outings: “It can take us two hours to round up everybody in the community for an activity so we've taken to doing smaller things like three people will go with a mentor to do something rather than the bigger groups. That seems to be working better these days.”

Starting in the spring of 2013, staff prepare lunch and eat with clients every Thursday, which has proven to be very popular: “We provide a nutritious meal for everybody and it fortifies them for the weekend.” Because of the high attendance by clients, staff have found that Thursday afternoons are a good to hold workshops or share developmental tools.

Staff and clients described many types of one-on-one support that mentors frequently offer to clients:

- Helping to plan a budget and going shopping on the day clients receive their money, to make sure they “buy the things they need before their addiction, perhaps, or someone else convinces them to spend their money in [other] ways”
- Finding “activities in the community for clients to express their strengths and interests,” e.g., taking a client who loves animals to volunteer at the SPCA, sewing classes, community art projects, parenting classes, community kitchens, the Mothers’ Centre, sports, and exercise
- Providing information about community and cultural events that clients can take part in
- Educating clients about sexual health and healthy relationships
- Helping clients with problem-solving; reminding them of their goals and evaluating actions that will help them to reach those goals
- Storing medications for clients to keep them from being lost or stolen, and helping them remember to take them as prescribed.
- Reminding clients of their appointments (doctor, court, probation, etc.) and taking them there, as well as running errands
- Assisting with finding appropriate schooling, upgrading or employment programs
- Assisting to find avenues for assessments such as SAC, Partners in Employment, Learning Disability Association, etc.
- Supporting parenting, providing assistance to deal with Child Protection issues
- Helping clients access City programs, e.g., reduced rate bus passes and free leisure cards
- Providing assistance in securing housing, helping to resolve issues with landlords
- Helping clients apply for assistance through the SAID program and making sure they get all the support for which they are eligible, e.g., rental supplements
- Advocating for services in a way that is appropriate for clients

Frequency of contact with clients varies greatly. A staff member explained: “Some we probably see almost daily, others it might be once a month. We try to connect with everybody in some way or another every week. That can just be a phone call or a text saying “How are you doing?” so that we can get feedback about how they are doing and so they keep us in mind. It’s hard to find the right balance . . . you don’t want to encourage people to be too dependent but you want to keep that relationship and have contact that is regular enough to encourage a good routine and to help problem solve at an early stage so that small problems don’t become big ones. So it’s a balancing act. It’s different with everybody depending on their needs and their wants.”

Connecting with other agencies is another important aspect of the mentoring program. Staff said they talk to people in partner agencies daily, especially Social Services, probation, courts, housing authorities, children’s schools, Mental Health, Westside Community Clinic. They explained that since they don’t have resources to provide training to other organizations, they try to work one-on-one to increase understanding of FASD. “Really what we do is a lot of finding someone who’s like-minded, who buys into it—believing a person has FASD or a cognitive disability—and who provides good service. Then we build a relationship with them and try to have them work with our clients as much as possible.”

Staff believe this approach is fairly effective and may work better than trying to train everyone, because some people just don’t seem to ‘get it’ no matter how much training they have. They have developed good relationships with many agencies, to the point that some will call the mentor before calling the client to schedule appointments or follow up, knowing that this is a better way of connecting with the client than trying to reach them directly. Staff members try to educate others about FASD whenever they interact with other agencies. They noted that most of the people who attend FASD conferences are already interested and involved, while those who could benefit most from learning about this disability are least likely to come to such events.

Clients of the mentoring program have access to a resource room whenever the CUMFI building is open. There they can play pool, watch movies, use the computer to play educational games, look for housing, or apply for jobs, do puzzles or play games, have coffee and chat with the Resource Room Coordinator and other clients. Clients also have access to other services CUMFI offers in the building, such as laundry facilities and showers.

The project coordinator mentioned that while it is hard to find the time for it, she tries to keep up with new research on FASD and has adapted the program based on what she’s learned about brain plasticity and influences on cognition (e.g., offering Cognitive Enhancement Therapy software; emphasizing good nutrition and exercise).

At the time of data collection, the program had 84 clients in total, 70 of whom were considered ‘active.’ Mentors’ caseloads ranged from 6 to 16, but some of these were families rather than individuals (e.g., one mentor reported 6 to 10 families, some of whom come to the program every day; another had 11 clients, with a total of 18 children). The project coordinator carries a caseload of about four clients who are too difficult for the mentors to work with, including one person who she sees out in the community because of her behavioural issues, in addition to her administrative role. About 70% of clients have FASD and the remainder ABIs.

4.3.3 Program reach

Publicizing the program: Staff indicated that in the early days of the program, they made efforts to publicize it, making presentations and setting up information tables at community events but at

present they are “trying to be low profile” because they have no room for new clients. Initially people didn’t know what the program was about, but now that it is well established, mistrust is less of a problem. Many of their referrals come through clients who already have a good relationship with the program; indeed, most of the clients we interviewed said that they had been told about the program by a relative. One staff member said, “We’ve been doing such a good job lately in advocating and developing relationships,” that they have been getting more referrals from other agencies, especially Probation Services.

Managing number of clients and caseloads: Staff explained that many of their clients have been involved in the program since it began. There is no ‘graduation process’—they are always going to need support, and once they’ve found it, they don’t want to go back to being without it. This contributes to a heavy caseload for all the mentors. The Mental Health Coordinator has started doing some mentoring to try to meet the demand. The original proposal suggested 11 clients per mentor, but staff felt that 5 to 12 would be ideal, depending on clients’ needs (e.g., single men require less time than women with children).

At one point, when they had reached capacity, they started keeping a wait list, and soon had 40 names on it. Two years later, when they hired another mentor, they phoned the service providers who had referred each of these individuals to see if they could get contact information for them and they were only able to reach three of those on the list. As a result, they have stopped keeping a wait list: “It gives people false hope of having a service that they’re really not going to get for a long time because the turnover is so low.” Staff are unhappy when they have to turn clients away but recognize, “If we want to keep the team that we have now, we can’t open for any more. But we are continuously introduced to new people that have a need so sometimes it’s a struggle.”

Distributing clients across mentors so that they all have a manageable caseload is very difficult because clients can shift back and forth from “maintenance mode” to needing much more attention quite quickly. Once the project coordinator examined all the case files and identified clients who were stable at that time; when she looked at the files three months later, “there was only one person still in maintenance mode while others who had been in a more crisis or active mode were in maintenance mode.”

Transferring clients from one mentor to another to even out the workload is undesirable because the program is “very relationship based” and both clients and mentors would find it unsettling. Staff members get to know each client so that they back each other up when necessary, but clients each have their primary mentor that they know well and with whom they develop a close relationship. Clients are almost always paired with a mentor of the same gender, but in the office, mentors will help each other out as needed.

Barriers to involvement: Everyone we interviewed indicated that they are aware of many people with cognitive disabilities, especially FASD, who could benefit from the program but are not

involved in it. The main barrier to greater participation is that the program is always at capacity. The psychiatrist said he used to refer patients there and would like to be able to do so but has stopped, because he knows they have no room. He wondered whether some people might not be aware that the program is not just for Aboriginal people. Another partner agency representative had heard that that the referral process was very slow and it could take months to get someone in. He also indicated that there are some particularly challenging individuals whom he would not refer to CUMFI, because he doesn't believe the mentors have sufficient training and skills to work with them.

Engaging and retaining clients: Staff explained that some potential clients never really engage. They have been referred to the program but don't really want a mentor, often because they don't like to be told what to do or they say they're okay with their lives as they are. Others come with an acute emergency and program staff are able to help them deal with it, but they don't become regular clients. Neither of these groups is reflected in the number of active clients.

The unconditional support offered by mentors is a novel experience for clients; as a result, some clients have trust issues initially and are difficult to engage. But staff find they're usually able to provide something useful in the initial stages that helps with engagement, by finding out clients' strengths and interests and their emergency needs. Staff do not carry out a formal assessment of new clients because that would put many people off; rather, they have an assessment form they try to fill in gradually.

Staff stated that most of their clients continue with the program once they've become involved. When clients stop coming, "it means that they're doing really good or it means they're doing really bad." Another staff member acknowledged, "It'd be nice to say that we're losing them to school and work but that's not always the case. It's usually addictions and housing. Or domestic violence. Or jail." Whatever the reason, clients often reconnect with the program when they encounter a problem they think the mentors can help with.

4.3.4 Strengths

Close, caring relationships: A key strength of this program is the staff, who demonstrate dedication to their job and compassion for clients. When asked why they were attracted to the position of mentor, one answered, "I've just always had a passion for helping people, trying to make a difference in other people's lives and doing what I can for them." Another said he'd wanted to have a job like that since he was young, so he could "be a positive role model for people that need it in their lives."

In spite of the many challenges inherent in working with the client population, several staff members said that the clients are a positive aspect of their work, e.g., "I'd say another part I like about [my job] is the relationships we build with the clients. I consider all of them my friends so basically my job [is] helping my friend."

The sense of helping others is a major reward of this work; staff know that they are “reaching a population that isn’t usually reached and that’s very satisfying.” The project coordinator claimed that the mentors are “very altruistic. There’s no other reason why people would be here except that, because they could get jobs elsewhere that would pay them more.”

The good relationships among staff members create a positive working environment, as one staff member explained: “I think that we have a really great group of people who work together and support each other. . . [A mentor] said yesterday, ‘You know what I like about us? Everybody just works their butt off.’ There’s lots of enthusiasm and passion . . . and dedication.”

In their relationships with clients, staff embody “the philosophy of being very respectful and non-judgemental,” in the words of the program manager. Clients’ comments on what they like about the program reflect this: “This is a good place and I enjoy being here.” “If you’re having a crappy day they’ll take you aside and go for coffee, sit down and talk to you about how your day is, how can they help you out. . . Someone is always there to listen to me about my problems.” “[I like having] someone there to talk to when you need someone to talk to, the support. Feeling cared about.” “I like it when every time I come here, I feel welcome. It’s like everybody is a family. Everybody is helping each other or trying to get through when people are struggling. . . [The mentors] are almost like brothers to me now.”

Flexible, holistic approach, focused on clients’ needs: The project coordinator sees the flexibility of the program as a major strength, because they are able to deal with pretty much whatever clients need, compared to other programs with more restrictions. She believes this also helps prevent burnout in staff, because they don’t have to say to clients, “That’s not our mandate.” Their “creative solutions” fund, which provides small amounts of money for miscellaneous needs, is a tangible example of this: “Having some flexible funding can make a problem go away and it doesn’t even take very much. It can take ten, fifteen, maybe fifty dollars, but if someone needs to have their birth certificate so they can get this and then they can get that, or if someone has damage in their apartment and they have to pay for fixing it, if you can help them get the materials to do it, help them fix it themselves, there goes the eviction notice, right? That’s really an important thing.”

She also believes that clients are more likely to engage with the program because staff are “non-judgemental, . . . more like a peer than a professional and not very directive,” and let the relationship with the client develop at a comfortable speed.

Help clients navigate system: Like the other support programs, one of the main forms of assistance mentors provide is helping clients find their way through social systems, something that would be overwhelming for them alone. For example, mentors help clients apply for assistance through the SAID program, and try to attend the assessment interview with them to ensure they are accurately assessed, because clients tend to conceal their disability. Staff work to keep up with the various programs that are available and make sure clients are getting everything they’re eligible for, like

rental supplements. They also help clients who are involved in the justice system to understand what's going on and what they have to do, e.g., terms of probation.

Trust in the community: Over time, CUMFI has developed a good reputation in the community, both among clients and other organizations. As one staff member put it, “We are a time-tested program. . . . We have worked very hard at building that relationship with other community agencies so the other community agencies recognize us.” Another said that “one of our really positive strengths is the trust that we have in the community—the trust from the clients. The clients come here and they know if they have a problem they'll trust that the advice that we're giving them is the answer to their problems. . . . The agencies that we've developed relationships with trust that we're working and acting on their best interest and the process is going to be easier with us integrated into the solution of whatever the issue may be.”

While not all organizations ‘get’ cognitive disabilities (see more under “Challenges”), some do, and staff say these are very welcoming and appreciative of their involvement. “[At] Social Services we hear on a daily basis, ‘Thank God for CUMFI.’”

Other services and amenities offered by CUMFI: Having the mentoring program located within CUMFI means that clients have easy access to many other supports. One of the most important is the Resource Room, a space where they can be comfortable and be themselves. This is especially important for individuals with cognitive disabilities, who often have a lot of trouble being out in public spaces. The only drawback, one mentor noted, is that it can be such a safe and inviting place that clients would rather be there than participate in programs or even attend school.

Having the Resource Room and a coordinator to oversee it provides an invaluable buffer for mentors, because when mentors are busy with one client, their other clients can engage in activities there. Staff mentioned that clients “fight over us and there's jealousy” when clients perceive their mentor to be spending too much time with others, and the Resource Room helps with this. The project coordinator believes the Resource Room enables them to be much more efficient: “I can't imagine trying to run the program without it.” A client commented that “[I like] being able to be somewhere and spend time and have coffee and just talk, watch a movie . . . somewhere to be.”

The support mentors give clients is supplemented by the services of other professionals at CUMFI. First is the Mental Health Coordinator, who is trained in trauma therapy. She tries to keep her schedule flexible so she can see clients promptly when they are having difficulties and prevent them from escalating, as well as providing ongoing counselling, and advising and supporting mentors. Second, having a mentor who could offer addictions counselling (currently on medical leave) has been an asset, as a staff member explained: “The more things that we can offer on-site the more chance there is that people will actually access the services.” Third, Dr. Mela, a forensic psychiatrist with the Saskatoon Health Region, sees clients regularly at CUMFI. This makes it much easier for clients to receive his services and the higher frequency of appointments enables him to better

monitor how their medications are working. One staff members mentioned that Dr. Mela has “the best approach with people” and really understands how to help individuals with cognitive disabilities. Clients’ use of medications is also aided by the fact that the staff will store the drugs for them and make sure clients are taking them appropriately, which saves money.

CUMFI provides clients with access to showers and laundry facilities. Staff explained that this is especially important for those whose lack of good housing can lead to hygiene problems which affect how other people respond to them.

As a Métis organization, CUMFI integrates cultural elements into its whole approach. A staff member explained that while their clients may be discriminated against in the community for numerous reasons—disability, income, race, sometimes gender or sexual orientation—at least at CUMFI they feel more comfortable as Aboriginal people. However, the mentoring program is open to individuals of any ethnicity, and staff believe that non-Aboriginal clients also feel at ease and welcome there (although, as mentioned above, the psychiatrist wondered whether they might be a need for more education about the fact that CUMFI services are available to non-Aboriginal people).

Opportunities for physical activity: The male mentors mentioned that their clients find physical activity, such as playing basketball and working out at a local civic centre, not only enjoyable, but very beneficial. They have noted clear-cut impacts on clients with anxiety and anger problems. For example, one mentor has a client who experienced severe anxiety when they were out shopping, but “after we go to the Leisure Centre he’s calm and he’s back to his frame of mind.” Staff did a survey with clients and found that involvement in physical activity improved overall quality of life, not just physical health. Engaging female clients in physical activity has proven to be more challenging, although the occasional client has enjoyed trying yoga classes.

4.3.5 Challenges

The nature of clients’ disabilities and concurrent problems: An underlying challenge to all support programs for individuals with cognitive disabilities is the way the disability affects their behaviour, as a staff member explained: “Their progress is not like a nice even chart. It’s really quite uneven from day to day. People can know something one day and not know it the next and it’s part of the memory and executive function and all that.” Another staff member commented that it is frustrating when clients do really well for a while and then slip up: “We have to continually remind ourselves that it’s a disability.”

Clients’ life circumstances add another layer of challenge: “They haven’t had many options . . . [and] many have limited ongoing supports in their lives. Friends and family may be more of a negative influence than a positive influence. . . And so it’s very situational as well. There’s just many, many [variables] that can’t be controlled.”

On top of their disability and unsupportive living situations, staff explained that many clients are also dealing with addictions, especially crack cocaine and unhealthy relationships, and with concurrent mental health problems (e.g., schizophrenia, depression, anxiety, bipolar disorder). Individuals with cognitive disabilities have a hard time remembering to take medications regularly, so this is a very challenging combination. Staff try to help by storing medications for some clients so they won't lose them, as mentioned above, but they are not always good at remembering to come in. One staff member commented that it can sometimes be difficult to know whether it is the disability or the mental health issues and history of trauma that is causing problems for clients.

The project coordinator noted that it can be difficult to see progress in this client population, referring to the analysis she had done of how long clients stay in 'maintenance mode.' "That can make it look bad for the program because, 'Can't we keep people in maintenance? What's wrong with us?' But really it is the FASD, but it's not just the FASD, it's the socio-economic situation that people are operating in. Just the FASD itself would . . . create a great deal of instability, but when people don't have a home or have so many negative influences or might be mugged or might get back into their addiction or whatever, it's very, very difficult to maintain stability."

Difficulties working with some agencies: While the good relationships CUMFI has established with some agencies are a strength of the program, as described above, the situation is not completely positive. Staff said that the lack of understanding of cognitive disabilities they encounter in other settings makes it harder for them to do their job: "They don't see [clients'] strengths. They don't see the gifts that they can bring to the table. All they see is that menace walking in the door. 'Oh, she's here,' or, 'Why is he asking me for cigarettes all the time?' They just don't understand that it's just the disability." One commented that some clients seem to be judged unfairly because of the FASD label, e.g., mothers who are trying to get their children back after being apprehended.

A staff member mentioned that while "there's lots of money being spent, . . . it's so often according to rules and regulations that are out of touch with peoples' needs." She went on to say that frequently, how the rules are applied "depends on the individuals working in those systems," which can be frustrating, because "different staff members from these systems allow different things. . . It is interesting to see that people who have a mentor or other advocate with them are usually given more time to explain their situation, get better services and are treated more respectfully."

Staff members expressed frustration with the agencies that don't 'get' cognitive disabilities, saying that "some of the organizations just butt heads with us." Some, like physicians, don't understand mentors' role and don't want them involved with clients because of privacy concerns. They may charge individuals for missed appointments and not be willing to take clients' disability into account. Staff maintain that when clients don't understand what service providers are telling them or asking of them, it helps everyone if mentor is there to explain and follow up.

A staff member further explained that it can be tricky to advocate for individuals with cognitive disabilities because they are often not obvious, and it would be inappropriate to come out and tell the service provider that the client has FASD or an ABI. In that situation, she said, “We just say, ‘We’re their mentor,’ and then people can come into their own conclusions. But we also have our staff cards. We’ve put our name and our contact information and just ‘CUMFI Wellness provides mentoring to people with cognitive disabilities.’ So the inference is there.”

Another example of this challenge is that while many clients have free access to civic leisure centres because they are low-income, in most facilities, mentors have to pay to come in with their client (unlike individuals with physical disabilities, who are allowed to have a helper accompanying them at no extra charge). The fact that a nearby civic centre has made an exception for their clients has enabled many clients to become more active.

On the other side, one of the partner agency representatives we interviewed mentioned that he has not had as much communication with mentors about shared clients as he would like.

Stressful work: As staff in the other programs noted, this is often stressful work and mentors risk becoming exhausted and burnt out. Staff commented that clients’ dependency on them can make it hard to set boundaries and maintain them; they are supposed to work from 8:30 to 5 but are available by phone outside those hours and may work a lot longer depending on demand (e.g., when a client is in hospital). One mentor gave the example of a client who had started attending school, but would leave school at noon to come and see his mentor, so the mentor had to meet with him at lunch time (and again right after school).

Staff noted that female clients in particular, most of whom have children, seem to continually be in crisis situations. Often their children are in care; they are trying to get them back, and have supervised visits with them, and this creates additional stress for their mentors.

The project coordinator commented that her position can be difficult because of the competing demands as an administrator who also mentors. As a result, she is “always caught up between creating the vision and being innovative and doing the paperwork and meeting the human needs.” As well, she finds “keeping staff healthy and doing their best work is another challenge.”

Funding limitations: While the mentors themselves did not mention this, both the Mental Health Coordinator and the project coordinator commented on the funding limitations as they affect staff. Wages are relatively low and mentors receive few benefits. The project coordinator wishes there were “some type of pension plan, no matter how modest. People will end up with an impoverished retirement even though they have worked hard throughout their lives.” As well, she says, “it could be a more family friendly workplace,” by offering mentors family leave to attend a child’s activities or stay home with children when they are sick. “I think that our morale would be better if there was that.” Mentors have a supplemental health plan but have to pay a monthly premium for it.

Moreover, the funding restrictions imposed by CDS prevent any increases in pay, which the Mental Health Coordinator criticized: “It’s difficult to retain long-term staff when you don’t have the ability to encourage them to stay through increments such as that. It’s solely reliant on the value that the individual sees in the job. The rewards that we get are the development of the clients and the flexibility and the role that we get to play in their lives.”

The project coordinator would like to be able to offer staff better remuneration, especially because some are single parents who struggle to make ends meet: “I feel like we’re not able to treat our staff as well as we should and . . . it’s kind of demoralizing for me . . . that we have no benefits and are working at probably 60%, if we’re lucky, wage levels of say Social Services or other workers out there.” However, in spite of this shortcoming, the CUMFI mentoring program has experienced much less staff turnover than the other programs we evaluated.

Mentors commented that they would like more money for arts and crafts materials, activities, and food for emergency situations.

Need for more staff development: The project coordinator commented that because the program got started very quickly, “we hit the ground running” and training of mentors has not been as systematic as she would have liked. Overall, she would like the program operations to be more methodical and systematic, with more regular staff meetings and retreats, but she acknowledges that it’s difficult to find time for this, when everyone’s available; meetings tend to focus on pressing issues. She would like to offer more staff development activities, and find ways to recognize small successes, which is encouraging for both mentors and clients, as well as showing staff that they are appreciated.

In a similar vein, one of the partner agency representatives stated that working with people with FASD requires a “high skill set,” and he is not sure the CUMFI mentors have enough training. From the “snippets” he has heard from clients, the mentors seem to act like a ‘buddy,’ and may not be realizing the potential to be a really positive role model, especially because people with FASD tend to be ‘followers.’ While he thinks the program offers a good service and he appreciates that it’s there, he considers it to be under-skilled. This relates to the previous challenge regarding funding, as he suggests, “if they had better benefits there and more money to pay their staff they could probably recruit higher-skilled people and I think that would go a long way.”

Hours limited to weekdays: Similar to other programs, staff commented on the difficulties clients face when their program is not open. They try to prepare clients for weekends, asking what their plans are: “We do some prevention stuff. . . Make sure everybody has got food for the weekend, they’ve been to the food bank, they have a safe plan for the weekend. Make sure the ones with addictions have solid plans that they’re going to be able to keep themselves safe and sober. Do our best for prevention and then pick up whatever on Monday.” A couple of the clients we interviewed said that they would like the program to be available to them in the evenings and on the weekends.

The project coordinator, on the other hand, said she is not sure whether having longer hours would make a difference. At first mentors used to keep their phones on all the time, but they didn't get as many after-hours calls as they expected. She thinks people are used to services being restricted to business hours, plus clients try to respect mentors' needs for family time and rest. The problem with extending hours is that "you don't want to make people completely dependent on you so they can't function or fill their time in any way on their own, because community inclusion is an important goal." She is trying to get away from telling clients they can call her after hours because she realizes it can lead to burnout.

4.3.6 Program impact

The clients we interviewed shared a number of ways in which they believe the mentoring program has helped them. One explained that her mentor is helping her look for housing. She said that "I've been more happier when I come here and just be myself. . . . I'm more stronger. I'm more talkative, more open." Before she came to the program, she said, "I was just really struggling and I was overwhelmed and had things built up," but now, "I learned not to set things off and let it pile up. Just get it over and done with." Another said that he has become less agitated; the program has helped him learn "how to be healthy and think straight and be positive. . . . Before I would either be on the streets looking for something to eat and now I got a place to live and being healthier and I'm going to the gym."

A third client explained that "now I'm at the verge of learning how to think about things before I react." She has had a lot of trauma, drug addictions, and anger problems, and still sometimes slips, but says is getting better at making good choices. "I'm able to tell [mentor] what's going through my mind and stuff like that. . . . Back then I didn't talk about anything that was going through my mind or how I was feeling. Now here I'm able to." She says that the mentoring program has given her "a sense of hope, a sense of connection, a sense of feeling loved and cared about. A sense of direction."

Another client attributes a lot of his success to living in CUMFI housing for the past four years: "Without that I probably wouldn't be able to get back on my feet because I would have nowhere to go." He says that whenever he has nothing to do, or has had some stress, "I come here. I know I'm not alone. I can actually get along with a lot of the people here. . . . It's keeping me . . . trying to not give up. Every time I come here I feel better. I feel like I'm trying to get somewhere in life. I'm getting the help I need. . . . without them I'm pretty much screwed. . . . Things are getting better but there's always ups and down. Everything works out and then I just go right back to square one. But with CUMFI they always tell me, 'Don't give up. You can do it.' It helps me to get back on my feet."

A staff member explained why it is difficult to assess the impact of these kinds of support programs: "It's preventive work—mentoring stabilizes people's lives and prevents extreme things from happening. Exactly what is prevented is hard to measure according to research standards but there

is no doubt that most people are doing much better than they were when they first became our clients.” Mentors believe that without this program, many of their clients would be in jail, on the streets, or dead. A client who had been homeless and whose two children had been apprehended explains how he was able to get into transitional housing through CUMFI and regain custody of his children: “Without the organization I wouldn’t have my kids and I wouldn’t be on the sobriety path. . . . Without them I don’t think I would be here today.”

The mentoring program, including the Resource Room, gives clients a healthier and safer alternative to their usual activities. A staff member explained that “having access to the drop-in centre helps people to meet their social needs in a positive, safe environment. This decreases the tendency for people to seek out or get involved with less positive influences that may include drug/alcohol use, illegal activities and unsafe situations. Our clients are very vulnerable to be taken advantage of in a variety of ways, and they can be easily influenced to take advantage of others.” One of the partner agency representatives said, “Probably most significantly it would be that they provide an actual space that the participants use, that keeps them out of drug use and that kind of stuff. So . . . they’ve replaced other activities that would be destructive to these people with something positive.”

Outside the Resource Room, a staff member suggested, the program “helps people to ‘try out’ and become comfortable with options in life that they have not had before. Assisting clients to get involved in positive community activities helps them to create their own natural communities, which promotes community inclusion, a significant goal.”

Two outcomes that staff believe the mentoring program helps prevent are involvement in the justice system and inappropriate use of emergency rooms: “Lots of our clients don’t know how to tell time at all. If it wasn’t for the mentors they would be breaching probation and breaching their terms of the court because they don’t know what time it is to meet the probation officer. That’s a huge thing for them because it’s keeping them out of jail.” Another staff member similarly stated, “Providing ongoing assistance prevents people from accessing the most expensive systems such as emergency rooms and the justice system. . . . We have seen that people with a mentor and able to spend time in the Wellness Centre are much more stable and have fewer emergencies, or the emergencies are more minor in nature.”

The project coordinator compared the mentoring program to a special project that CUMFI had some time ago, which enabled them to hire a person to work full-time on justice issues—taking people to see lawyers and to probation appointments, working out community hours, and going to court. When the funding ended after a couple of years, they realized that even though their client base had increased, justice issues had decreased to the point where they didn’t need a full-time support person any more. “We hope that means that mentoring support got people to a place where they were having fewer or no conflicts with the justice system.” She reported that they have

seen similar declines in the demand for mental health services over time, because ongoing counselling and support stabilizes clients and prevents crises.

The psychiatrist we interviewed said that his sense is that “the impact is positive for the patient [and] . . . it is good for the community in that the clients are not eating up a lot of the resources either through going to jail or going back to hospital. There are tons of stories that you will hear of how patients have done very well.” The project coordinator pointed out that mentoring also saves money in comparison to CDS funding, because the amount spent per client in a mentoring program “is significantly less than what they would be awarded according to their assessed level as individualized funding through CDS.”

As well as helping clients avoid unnecessary use of expensive services, the project coordinator claimed that the mentoring program enables them to access helpful resources: “Mentoring creates an avenue of access to programs and resources for our clients that they would otherwise have trouble accessing, especially on an ongoing basis. Assistance with making and keeping appointments and ensuring good communication between client and service provider is very helpful. They are also much more likely to try something new if they have their mentor go with them, especially for initial appointments.”

Many clients of the mentoring program are unable to find and keep regular employment. One mentor said that his “biggest success story” involved a client with a brain injury who “comes off as if he’s intoxicated, he staggers, he slurs his words” but with the help of his mentor, held down a job for almost two years.

An important life skill that mentors help clients with is money management. A mentor told of taking a client had just gotten her kids back to Walmart, and while the mentor was helping another client she’d run into, the first client spent all her food money on gifts for her children. When the mentor found out, she helped the client return these items so she could afford food. “If I hadn’t been there to re-route that she would’ve gone without food.” Staff also noted that they watch their clients who are addicted especially closely, so they don’t spend all their money on their addiction.

The mentoring program provides education and support around numerous aspects of lifestyle, including safe sex, nutrition, healthy pregnancy, and parenting. Mentors cited helping clients use birth control successfully as an example of the program’s positive impact. Reducing substance use is another: Mentors said that some of their clients had avoided using for months, which for these individuals is “a huge thing.” One added, “I’ve also had a guy that’s been sober for over two years. He recently had a slipup but he’s trying to beat his record.”

Finally, the Mental Health Coordinator recounted the story of a particularly difficult client, who has schizophrenia and post-traumatic stress disorder and is “extremely aggressive. The communities are

absolutely terrified of her, to say it frankly.” This woman’s mentor “has done a lot of work with her in integrating her into meaningful opportunities in the community. Not just, ‘Let’s put her over here so that she doesn’t scare anybody,’ but meaningful opportunities where she’s feeling useful. . . She cooks here. She bakes here sometimes for the clients. We involve her in big projects. It’s difficult because of her personality . . . but she feels so much value in that.’ The staff have seen a big change in this client over the three years that she’s been involved in the mentoring program. “Now she is able to actually filter and reflect some of her responses to things that she would normally explode on.” She used to frequently visit the ombudsman, “standing in the middle of the office and screaming her head off and nobody is able to make sense of her because of her disorganized thought pattern,” but now can have “ongoing conversations. . . It’s been fantastic. She is benefiting greatly to where she is getting her life in order . . . I don’t think she would have been able to accomplish [this] without the [program].”

4.3.7 Increasing effectiveness

The main way in which the individuals we interviewed felt that services for people with cognitive disabilities could be improved is by expanding the mentoring program. Staff, clients, and the psychiatrist agreed that more mentors are needed. In particular, they noted that once the new Mental Health Court is fully underway, the demand for their services is likely to increase dramatically.

Staff commented that if they were to take on more mentors, they would need more space. As it is, mentors share offices, which can be problematic. Some clients feel anxious in crowds so when resource room gets crowded, they’ll leave, and when they have group events, like their Thursday lunches or holiday parties, “it’s a zoo.” The project coordinator noted that there is a limit to how many mentors she can effectively supervise. For these reasons, she thinks it might be preferable to establish a similar program in a different organization in another part of the city rather than to expand the CUMFI program.

As noted under ‘Challenges’ above, one of the partner agency representatives suggested that the funding for the mentoring program should be increased so that more highly skilled mentors can be hired. Similarly, the psychiatrist said that it is important to support the program by “training and selecting the right qualities of mentors” along with “regular training and updating of skills of the new things happening in the mentoring field,” which require “supporting the financial sustainability of the program.”

In addition to increasing the number of mentors, staff had many ideas for additional services they would like to be able to provide to clients, include on-site schooling (e.g., computer classes), nutritional counselling and a breakfast program, and a bigger and better exercise room. The project coordinator is working on a part-time employment program for clients, believing this would help them greatly by getting them occupied with a positive activity, giving them some extra income, and

connecting them with employers who will see the benefits of using these individuals for short-term work. “Employment also builds self-esteem and helps people feel like they’re participating in the world around them.” She added that “the sky is the limit as far as how innovative the program could be, or the number of appropriate initiatives that could be undertaken. We have so many great ideas and interests but are limited by time, budget and energy to follow up on too many of them.” The best case scenario would be for clients to find a “natural community” so that they wouldn’t need as much support from mentors, which, the project coordinator explained, is part of the rationale for their employment program, and everything they do.

Housing is also seen by staff as a major problem. Clients often don’t have good credit ratings, and rent is high. Some who are homeless use jail as a housing solution for the winter. CUMFI runs 16 units for men in addictions recovery, but staff see a need for more units. “A lot of clients can live independently. They just need a little support. They’re not too far gone where they need a group home but they’re not well enough where they can live independently.” A partner agency representative thinks what is needed is a 24-hour professionally staffed facility for individuals who have FASD and are homeless, which would include a detox component. “That would be probably really helpful because . . . they could be assessed, they could be stabilized, they could be sober and then someone could help them transition into more stable housing and connect them with services.” Staff also mentioned a need for quicker access to detox programs. At present, the wait time varies greatly and seems to depend who they speak to.

The project coordinator explained that it is difficult for adults to get an FASD diagnosis, because physicians and neuropsychologists trained and funded to do these assessments have only become available recently and their waiting lists are long. Furthermore, “FASD diagnosis is a team diagnosis, that requires assessments by speech-language consultants and social and vocational workers, so there is still only partial funding for diagnosis.” The psychiatrist concurred that access to diagnoses is difficult, and that “provision of diagnostic teams that utilize mentoring as a component is crucial . . . so that they can be helped appropriately.” He also mentioned that Saskatchewan needs to have an FASD strategy similar to that developed by the Alberta government in 2008, along with a research arm in order to evaluate its effectiveness.

4.4 FASD Support Network of Saskatchewan Family Support Program

The Family Support Program is targeted at families of children (of any age) with FASD as well as unattached individuals with this diagnosis. Unlike the first two support programs presented here, it is not a mentoring program.

4.4.1 Evaluation participants

The Executive Director had only been in her position for eight months of the time of our interview, having moved to take the job from another province. The three family support workers are all female, and had been working in that role 3-18 months.

We interviewed representatives of three partner agencies: an employee of the Saskatchewan Association for Community Living (SACL), an employee of the Saskatchewan Prevention Institute (SPI), and a psychologist, who had been doing FASD assessments for adults through the Saskatoon Health Region for the past 18 months.

We also interviewed clients of the Family Support Program: an individual with two adopted adolescent children, who has been involved with the program since 2013, when the children were diagnosed with FASD; and a couple with an adopted adult son who was living on his own when they first contacted the Network, about three years ago, but has since moved back to live with them.

4.4.2 Program delivery

Like the other support programs we evaluated, this program is focused on clients' needs. It is distinct, however, in that it provides services to families, as well as adults with FASD whose families may or may not be involved, and there are no age restrictions. Staff indicated that their clients include birth, foster and adoptive parents, as well as families that are caring for nephews/nieces, grandchildren and great-grandchildren. "Many of the birth families that come to us live with FASD in multiple generations."

Because of the client-centred nature of the program, the level of contact varies, but support workers indicated that they would usually contact families at least once a week, if they haven't heard from them. Much of their contact is by phone or e-mail, and the time of each contact generally ranges from 30 to 90 minutes, sometimes longer. In addition to this one-on-one support, workers spend a lot of time researching, advocating, and helping clients apply for funding, as well as running group activities, described below.

Individualized support starts with workers setting goals with clients, then creating a plan with them to help them attain these goals. They develop behavioural interventions for families, helping them understand their children's behaviour and implement strategies to improve it, and they provide educational resources. Workers may have to advocate for services (e.g., in the school system and justice system) and if necessary, will attend appointments with clients to help them navigate the system. So the program has some similarities to mentorship programs, but support workers emphasized that they see this as a process of modelling, with the aim of clients learning how to manage things themselves.

Support workers help clients obtain funding through CDS, which they describe as a lengthy and complex process. If funding is approved, they advertise for a mentor, interview applicants, and then connect clients with suitable individuals, to help them find someone who is a good fit: “We make sure that the mentor and the client sync up together.” Technically, clients hire the mentor, but the support workers guide them through the whole process. One commented that it can be difficult to find mentors because the work tends to involve irregular hours. Even after mentors are hired, Network staff continue to be involved, training, monitoring, and supervising the mentor, acting as a liaison for mentors with CDS, and sometimes as a liaison or mediator between mentor and family. Clients may also use CDS funding for respite providers or therapeutic writing or art therapy, music therapy, or occupational therapy.

Support workers play a similar role in assisting clients to apply for support through SAID, helping them fill in the applications and then accompanying them to the meetings with the assessor. They see this as important to ensure that clients are accurately assessed because they sometimes hide their disabilities.

The Family Support Program offers several opportunities for clients to meet each other and obtain support and information in a group setting: a monthly Family Support Group meeting for parents/caregivers of someone with FASD; annual parents’ retreat and sibling events; and conferences. Support workers are also involved in providing a caregiver workshop throughout the province. One gap that staff identified is that the Family Support Group is intended for parents who do not have FASD themselves, and indicated that “the Network is in preliminary discussions about what a support group for individuals with FASD could look like and how best we could meet the needs of those who are living with FASD and those who are both living and parenting with FASD.”

While most of the services offered through the Family Support Program are limited to families living in Saskatoon and surrounding areas, support workers have also been involved in establishing peer support system for families in other parts of the province, with the intent of setting up Family Support Groups in smaller communities. At the time of this evaluation, a group was running in Prince Albert, and discussions were underway in Estevan and Fort Qu’Appelle. In response to difficulties they experienced initially in establishing such groups, in the past year they have been trying a new approach, holding Caregiver Workshops in smaller communities which focus on education and connections. Parents of children with FASD are invited for an evening of learning about FASD, coping strategies, self-care, and peer support. These workshops are carried out with the help of an organization in the community that is interested in helping a support group evolve from the workshop, or a group of parents who plan to commit to meet on an ongoing basis. The intent of this approach is to help reduce the shame and stigma around FASD and show parents they are not alone. In addition, the community based supports enlisted are able to help the group by taking care of the organizing for the first while.

Support workers interact with many other agencies daily, finding out how they can help their clients, advocating for clients who are using the agencies' services, and educating about FASD in an attempt to build the capacity of other organizations to be more helpful for individuals with FASD. The organizations they have the most interaction with include CDS, Partners in Employment, Partners for Workplace Inclusion Program, school divisions, and the Alvin Buckwold Child Development Centre. They also have a lot of contact with the psychologist who conducts FASD assessments for adults and will help clients arrange these assessments.

At the time of the evaluation, the program had a total of 23 active families (6 to 9 per support worker).

4.4.3 Program reach

Publicizing the program: Staff indicated that they are not currently trying to increase enrollment in the Family Support Program because they have no room for new clients. However, they want the public to be aware of the Network and all their services, and to increase awareness and understanding around FASD generally, so they publicize their services through word of mouth, community workshops, exchanging information with other professionals, and building partnerships with agencies. The Network's Community Education Coordinator, Communications Coordinator, and Special Events Coordinator, while not involved in the Family Support Program directly, all engage in outreach.

Particular efforts are being made to connect with smaller communities, which has proven to be more of a challenge. Ideally, someone from a community would invite the Network to come and provide the Caregiver Workshop, but the stigma associated with FASD can make this difficult. Staff have been focusing recently on offering workshops for professionals in other parts of the province, hoping they will contact families they know are living with FASD, to facilitate the Network coming in to offer their Caregiver Workshop.

Managing number of clients and caseloads: Staff indicated that families who are referred to the Family Support Program when it is at capacity may be added to their wait list, and if interested, they will be mailed a semi-tailored package of FASD information. The support worker finds out the type of services the family is looking for and sends referrals or information to the family as appropriate, even though they are unable to take them on as a client at that time.

As in the other programs, workers explained that the unpredictability of clients' lives makes it hard to classify files as 'active' or 'inactive.' Clients "have a new day every day and they don't know what they're going to expect." The frequency and intensity of contact can vary dramatically, depending on what's going on with the family; if they get a mentor and start working towards goals, support workers may not hear from them much, while at other times it can be daily contact. This makes it

hard to know the ideal number of cases to take on. Support workers felt that sometimes their caseloads were excessive.

Barriers to involvement: Partner agency representatives, staff, and clients mentioned several reasons families living with FASD might not get involved with the Family Support Program. The most obvious is geographic, since the program is mostly limited to the Saskatoon area. Another important one is thought to be the stigma associated with FASD, whether it is an individual realizing and acknowledging that he or she has this disability, or a family seeing it in their child. As one client mentioned, this can be easier for adoptive families because “they didn’t cause it.” A staff member said that clients are sometimes referred to them by others, but they’re not really ready to talk about FASD.

Many of the families the Network works with live in poverty and so may be too preoccupied with meeting their basic needs to seek out disability-specific services. As one staff member explained, “Often I would say that the clients that kind of fall through the cracks, it’s because of poverty issues or homelessness issues or transience.” A client and a partner agency representative both felt the location of the Network office in the north end of Saskatoon is less convenient and accessible than the inner city. The client also mentioned that not offering childcare at parent events could make it difficult or impossible for some parents to participate, arguing, “I think it’s a cost you have to eat as part of trying to reach the people who really need the service because they can’t leave their kids home [and] they can’t leave them with other people.”

4.4.4 Strengths

Providing understanding and hope: A staff member explained that “Often families come to our organization when they are in crisis or facing burnout; they have often exhausted (or become frustrated) in accessing other services and are looking for help.” In this context, the understanding and support offered by the Family Support Program is a marked contrast. As the clients put it, their first contact with the support worker “was such a breath of fresh air. We just never had anybody who understood [son], who supported us and encouraged us. . . . She seemed to really be able to identify with the things that we were experiencing. She kind of gave us hope.” They greatly appreciated the fact that the support worker “got the whole picture” and “understood where we were at,” as well as her ability to explain things to their son tactfully and positively, which has increased his receptivity. Even the receptionist at the Network was kind and helpful, which meant a lot to them. “It was just like they went the extra mile for us all the time.”

Offering timely and appropriate support: A staff member stated, “I would say the strengths are that people can access us and get services within a timely manner. Most people are coming here . . . in crisis, so they need that immediate intervention.” The clients we spoke with agreed that the ability to access their support worker when and as much as they needed to was a great asset. The couple we interviewed said they sometimes felt like they might be imposing on her, though she

didn't make them feel that way. They appreciated getting support even though their son was already an adult.

A staff member commented that "one of our strengths is flexibility, for sure. We're able to meet their clients where they're at."

Connections and advocacy with other agencies: A large part of the support workers' job involves helping clients 'navigate the system,' and this seems to be working well. One staff member said, "I think we have a strength in reaching out to our partners and to the other service providers that are helping our clients."

Clients spoke of the difficulty they experienced trying to figure out how to access helpful services and programs for their children, before they had the help of the Family Support Program. "You basically need somebody who's not living in the trenches to have a clear head to point you to things . . . There is no centralized place. . . the school stuff isn't in place, after school programs, the health care system, nothing's in place. It's all this random jumble of hit and missed things and without a FAS support worker to give you a few tips, you have no idea where to go or who to ask." This client mentioned that the support worker has "been good when I hit a roadblock with like the education system or something to give me a name or a program that I can go apply to. You've got another voice out there that says, 'Okay, somebody's FASD kid did quite well in such and such and this location and talk to so and so.' That networking piece of it is really important and useful."

Similarly, the other clients found their support worker to be extremely helpful when their adult child was dealing with legal problems; she supported him, advocated on his behalf, and educated others in the justice system about his needs, and they believe her help prevented their son from having a criminal record. Their experiences trying to get help for their son from the school system and the health care system had been very negative and frustrating, so their support worker "kind of made up for 35 years of no help from anybody. We were just hanging on to her like, 'Oh, my goodness. Thank you, thank you, thank you.' She was just a lifeline for all of us."

The partner agency representatives we interviewed considered their relationships with the Support Program to be very strong. One commented that the Network is "very much working on being a very professional organisation" and that she appreciates their efforts to keep her organization informed of the Network's activities and avoid overlap. The psychologist finds that having support workers connected with individuals facilitates both having the assessment done by him (because they usually need support just to manage the logistics) and also then following through on recommendations. "The support workers are really kind of vital in helping the person kind of implement them." His opinion of the Family Support Program is 'excellent.'

Offering peer support through parents' events and groups: Clients spoke very positively of both the monthly Family Support Group meetings and the annual parents' retreat. The opportunity to meet with other parents each month not only allows parents to get more information on managing

FASD, but also “to tell your story and hear other people’s stories and understand and share.” The group meeting focuses on the participants’ needs: “It isn’t just a formula. It really meets the people in the room where they’re at.”

The same client described the parents’ retreat as: “That 24 hours where you’re not with your kids, an incredible little diamond of an event.” As well as providing respite, [staff] “work really hard in organizing sessions there that you can pick and choose from that meet the needs for your kids and your own mental health. . . They do a good job of bringing in outside agencies and experts that could help.” The other clients also found this retreat very educational and encouraging, after years of frustration and challenges: “Things started to come together. It was like . . . we were starting to get puzzle pieces that we’d been missing for years. . . It was wonderful.”

Staff believe that peer support is especially valuable for families living outside of Saskatoon and in rural communities: “Being able to connect a parent with another parent with similar experiences lets them know they are not going crazy . . . and . . . decrease feelings of isolation.”

The parents who attend the monthly meetings in Saskatoon “have become advocates for each other. They discuss how to access different services, what has worked and what hasn’t worked from a parent perspective and how to emotionally cope with what may be taking place at home.”

On the other hand, the stress of parenting children with FASD can find it difficult for clients to effectively support each other, as one client who had been matched with another family noted: “The other person has been overloaded and I’m overloaded, too. . . we’re just too overloaded with some crises of our own at the moment to even pick up a phone and have a conversation.” However, this person still believed that the peer support approach is an “awesome” idea and “it’ll work eventually, they shouldn’t quit doing that.” Staff acknowledged that “the difficulties surrounding support groups in different communities are incredibly vast, but rooted in the shame and stigma that surround FASD and the already high demands on parents caring for a child/ adult with FASD.”

Educational focus: All the activities mentioned as strengths above involve elements of education, which is a central component of the whole FASD Network that Family Support Program clients benefit from. The executive director explained that she is well supported for professional development and so can go to national and international conferences and learn what others are doing, which feeds back into the program. One client reported that the information the Network provides on its website and in booklets has been very helpful, both in terms of helping to explain FASD to the school system and to other family members, and also to educate her children on exercise, nutrition and other topics.

One of the partner agency representatives commented that the Network staff has been doing a very good job recently of getting out into the community, networking, attending meetings and conferences, and “doing training all over the place.” She felt that their newsletter and the other materials they produce are of very good quality. A staff member said, “I think that the ability to

educate and to teach other professionals about FASD . . . is a really good part of it.” (This is described further under ‘Program Impact.’)

4.4.5 Challenges

Several challenges were mentioned by staff, clients, and partner agency representatives, most of them common to all the programs examined in this report.

Nature of the disability: Staff acknowledged that the nature of the disability and the living situations of the families dealing with FASD create challenges. Keeping in touch with clients can be hard, because their phones may be disconnected, they may not have stable housing, and they sometimes forget appointments. Related to this is the fluctuation in demands for support workers’ time, as clients move in and out of crisis, which sometimes results in an unmanageable work load. One client commented that while support workers do the best they can, sometimes they have not followed through on things they have promised to do, which can be very difficult for families in crisis.

Staff turnover: The program has experienced considerable staff turnover, especially in the position of Executive Director, which has seen three individuals in the past three years. As a result of this change in management, the program has not had consistent direction. New staff take time to be trained and to “get up to speed,” as a partner agency representative has noticed. She suspects that the Network positions are “stepping stone” jobs: “It’s a great place to get a job and to start out, but if they don’t have the salaries to keep people they will have a turnover, which will make it harder to provide the consistent support [that clients need].” Staff members acknowledged that “money is always a factor.”

Job stress: Staff admitted that the work can be very stressful and may lead to burnout. Not taking things personally when dealing with clients in crisis can be a challenge. On the positive side, one noted that job benefits (personal days, sick leave, holidays) really help with this: “I appreciate that aspect of my job, because I know that I have time to myself, and that my health is of concern to our organization.” Staff members also feel that they get good support from each other, informally and through bi-weekly meetings with the program manager.

Need for more one-on-one support/mentorship: For some clients, what the Support Program offers is not enough—they want the support worker to be a mentor or taxi driver. The staff have experienced some difficulties in helping clients find and retain mentors, using CDS funding. “Some of those things are systemic and some of them are just bad luck.” They would find it very helpful to have a pool of mentors to draw on. It would be especially value to be able to set up “immediate short-term mentorship, because a lot of the families that access our services come to us in crisis so that’s when they’re looking for their support. The three of us do our best to kind of be that mentor while balancing the case management role but for some of our clients it’s been a year since we’ve

requested the DLSA and things haven't been approved." Staff wish that the application process for CDS (and other assistance programs) could be simplified, to reduce paperwork and delays. One client voiced frustration about the difficulties she had encountered in trying to hire a mentor for her children; because her family was above the income cut-off for CDS, not only were they not eligible for funding, they could not access the Network's list of mentors.

The Executive Director believes that it would be beneficial for the Network to have mentors on staff and is hoping to make that happen; one of the partner agency representatives agrees that this would be a good addition to the Support Program.

4.4.6 Program impact

The clients we interviewed were unequivocal about the difference the Support Program had made in their lives. One said, "Oh, it's the difference between sanity and insanity. It's the difference of the kids being at home and maybe not being at home, like, it's huge." The others echoed this feeling: "There is absolutely no question that they have been of tremendous help to [son] and to us." They question how their son would have got through the legal crisis he experienced without the help of their support worker; they believe he would have probably lost his job and never gone back to work. "[The Network has] made a fantastic difference. . . We've had hope and answers. We've gotten answers for when we needed answers and understanding that we've never had." Both sets of clients hope to remain involved with the program throughout their children's lives "because the struggles don't go away, they change."

In terms of specific changes, one client explained that her support worker (along with the parent retreat) "has been really good in helping us make that shift to thinking about sometimes you need to change the environment rather than the people. That's a huge piece in FAS. It's just made big differences in our sense of well-being and the kids' level of contentment in the house and stuff."

Staff listed many ways in which they have seen the support program help families: clients have become re-engaged in school and/or completed high school; parents have regained custody of their children; individuals have "navigated through the justice system, completed programming specific to their charges and have not reoffended"; clients and their families have become better able to advocate for themselves; individuals have been supported to have healthy pregnancies; families in crisis have accessed funding and are able to return to their baseline level of functioning; and clients have been able to receive assessments and diagnoses which have helped them and others understand their behaviour better and put strategies in place.

A staff member shared some specific success stories: "I have a young man who became disengaged from school and wasn't allowed to go back until he had met certain goals and so through this program we've been able to get him re-engaged to a school [and] stabilized in terms of his medical and mental health. . . I've also got a couple of adults . . . who, through the money that we've gotten

through CDS and being able to put a mentor in place, have been able to have healthier pregnancies and healthier relationships in the community in terms of accessing services and just being a contributing member.”

While many families need long-term, intensive support, this is not always necessary. A staff member gave an example of an individual who was helped by just one consultation with a support worker: “Sometimes just having somebody to talk to and knowing that you're not alone out there” is enough.

Representatives of partner agencies also had positive opinions of the work the Family Support Program is doing. One said that while she is not directly involved with clients, she knows of people who are connected with the FASD Network and has never heard anything negative: “I would say that yes, it’s having an impact. It’s just an incredibly challenging population.”

The psychologist mentioned specifically that support workers have helped individuals who are having legal problems, sometimes with input from him, to provide information to lawyers or police which has enabled their disability to be taken into account. This speaks to another goal of the Family Support Program, namely strengthening existing services and programs so that they work better for individuals with FASD. A staff member believes that there have been “huge gains in many areas of service delivery, but there is still a long way to go.” Their aim is to effect change from the bottom up, by making frontline workers in various systems aware of the services the Network offers, developing their capacity to recognize FASD as a contributor to problem behaviours and to support individuals with FASD. This educational work is done by all components of the FASD Network, including the Support Program.

4.4.7 Increasing effectiveness

One of the clients felt that a lot more could be done to coordinate services for families coping with FASD. She contrasted her experience with her mother being diagnosed with Alzheimer’s, in which “someone contacts you regularly with all the next steps that you may or may not need and the agencies that you need to go to and what you can expect there and like, it’s all very clear cut, one-stop shopping,” suggesting that parents of children with FASD would benefit greatly from a similar kind of coordinated approach.

The clients whose son is now an adult wish that more resources had been available earlier in his life, but said, “Boy, are we thankful that the provincial government saw fit to put money in this enterprise.” Based on their son’s trying experience with the justice system, they would like to see more training for lawyers and judges around FASD, to be better able to take the needs of people with FASD into account, saying that the current system is “trying to fit squares into round holes, square pegs into round holes. . . . They need an advocate. They need a system that works for them.”

Network staff would very much like to expand all of their services, including the Family Support Program, to the whole province, and are working on this. They identified a number of additional services they would like to have available to their clients: more assessment centres, incorporation of professional services like occupational therapy, speech and language pathology, and art therapy into their program, and more services and support groups for individuals living with FASD (which is another area they are working on). The psychologist agreed that more support workers, in more areas of the province, are needed.

Finally, staff expressed a desire for the Network to gain more recognition and have a stronger voice so that they can work more easily and effectively with school and justice systems. “Moreover, we need to continue to set a climate of acceptance and awareness across the province so that we can continue and expand the conversations we are having about FASD.”

4.5 Regina Community Clinic Life Skills and Addiction Program

This program has a slightly different focus from the others we examined, offering weekly group programming for adults with FASD as well as individualized support.

4.5.1 Evaluation participants

The program manager has worked at the Clinic in the area of FASD since 2004 and established the Life Skills and Addiction program. The two coaches, one male and one female, had both just started work in the past month at the time they were interviewed, and consequently had a limited ability to reflect deeply on the program. We also interviewed the physician who conducts FASD assessments and diagnoses at the Clinic, a probation officer, and an employee of the Ministry of Social Services who works with youth up to the age of 21. All three of these individuals make referrals to the program.

We interviewed three male clients and two females, who had been participating in the program between eight and eighteen months, as well as the parent of another client, who has received services from the Clinic’s FASD Centre since it began. Two of the male clients are required to attend the program as a condition of probation.

4.5.2 Program delivery

The Life Skills and Addiction Program offers clients a variety of opportunities, depending on their needs and interests:

- An activity room where clients can play games, socialize, and access a computer
- One-on-one support from coaches, including referrals to other programs and system advocacy
- Group programs (men’s, women’s, and addictions and recovery), one afternoon a week

- Outings in the community (e.g., to the Science Centre, art gallery, bowling, grocery shopping, local events)

Staff explained that the frequency and type of involvement is decided by the client. Some come every day and spend the whole day there; others drop by once or twice a week. Clients are encouraged to participate in the group programs, but not required to do so. Some clients do not function well in groups, due to the nature of their brain injury: “They are unable to maintain several levels of boundaries, may mix up another’s information with their own, and may have attentional impairments that prevent them from participating in the group, and sensory integration deficits. And they may be very disruptive to the group.”

Attendance at the weekly groups varies, but there are usually four or five clients participating (the space limits participation to about six). The activities are tailored to the interests and needs of the group. Clients may attend the program for as long as they wish.

Outside the group programming, clients come to the clinic when they need help with a specific task, such as filling out a resume, reading the newspaper or looking for housing, or simply “because they have nowhere else to go and want company and to do something normal (e.g., cribbage game with coffee),” as a staff member explained. The activity room provides a safe and comfortable space for clients to spend time, interacting with each other and with staff.

Coaches help clients in many ways: helping them find things to do in the activity room, providing assistance with the kinds of tasks mentioned above, listening, helping them access other services and supports both within the clinic (e.g., nutrition and exercise therapy, medical care) and outside (e.g., referrals to Saskatchewan Assured Income for Disability (SAID) program, Ranch Ehrlo, accessing mentor through South Saskatchewan Independent Living Centre (SSILC) or AFSC, Paratransit) and sometimes doing errands or attending appointments.

In addition to providing direct service to clients, staff regularly connect with other agencies and organizations. They reported that the program “has always been based on a very strong partnership model and that is working well.” This is particularly important because this program focuses on life skills rather than mentorship; they have found through trial and error how much case management they are able to take on without becoming overwhelmed, and try to connect clients with other agencies that are able to provide more one-on-one support. The program manager frequently makes presentations to a variety of agencies and organizations on FASD, including information on their program. Staff e-mail partner agencies a couple of times a month to let them know the activities and events offered by the program, encouraging them to share this information with their clients. Phone conversations with other agencies about mutual clients are another means of communication, with one partner agency representative indicating a desire for program staff to be more proactive in calling. The program has a particularly strong relationship with Probation

Services: the program manager spends an afternoon at the Probation Services Office every two weeks consulting with probation officers about clients and meeting new clients; probation officers go to the clinic at a similar frequency so clients can report in with them rather than having to go to the probation office; and probation staff have provided information to clients in the group programs.

At the time of this evaluation, the program had about 93 clients, including some new referrals staff were still trying to contact. Of these, they considered about 50 to be “active files,” and of these, there are 15-20 clients who routinely participate in the program.

4.5.3 Publicizing the program, recruiting and retaining clients

There has been no difficulty in recruiting sufficient numbers of clients for the program; rather, the challenge is in maintaining a manageable number in relation to the physical space and staffing levels, and keeping track of clients whose lives are unpredictable and transient.

Publicizing: The program is publicized through presentations and emails to other organizations and word of mouth through colleagues and clients. As previously noted, probation officers are a significant source of referrals, requiring attendance at the program a certain number of times per week as part of an individual’s case plan.

The program manager is very involved in making presentations on FASD and the program to whoever requests them, as mentioned above. While this has been effective in raising the profile of the clinic’s FASD Centre and the program, it is limited by the fact that those who request presentations and those who attend them are already interested in the topic; there are others who “don’t believe” in FASD.

Managing caseload: Publicizing the program generally leads to a “flurry of referrals” which creates more work and clientele than the program can handle, because of its limitations in both physical space and staff. Keeping a manageable caseload is challenging because of the unpredictable nature of FASD. “It’s easy to say we could take more clients if everybody is stable and if everybody is in a good space. But all it takes is three clients . . . to need a lot of support and we’re running.” Staff need to be accessible to clients when they are in need in order for the program to be successful. “There’s always a fine line between being really, really busy and not being able to meet someone in a crisis or being a little more cautious in our caseload and being able to meet their need.” This situation has been compounded by the difficulties the program manager has experienced in retaining a full staff complement. The ideal number of clients is thought to be 15-20 clients per staff member.

Barriers to involvement: Evaluation participants agreed that there are many individuals with FASD who are not involved in the program. Barriers to participation (and even awareness of the program)

are inherent in the nature of FASD and the lifestyle of many people with this disability, i.e., limited cognitive abilities, lack of support systems, transportation and telephone access, and transience. Greater understanding of FASD in social service agencies and other institutions, including the corrections system, is needed, because many individuals experiencing problems are not recognized as having FASD and therefore are not referred to the program.

Those who are most likely to attend the program and benefit from it tend to have some additional supports, an FSIQ (full scale intelligence quotient) above 60, and a certain level of emotional maturity. A staff member explained: “The clients who do well with us are clients who already have some supports out there. So they have someone else to help them get there, or they have someone who will remind them to get here. Whenever we have that kind of support we see those clients far more often. But if we’re their only support they’re on their own when they’re not with us and that’s very challenging. So you know our ideal client would already be connected but a lot of them aren’t.”

Some individuals with FASD have needs that are too great for the program. Partner agency representatives mentioned that they do not refer clients with a history of violence or behavior problems that make them too dangerous to participate in the program. In addition, the program is perceived by partner agencies as requiring group participation, and so they will screen out individuals who they believe would not function well in groups. In the past, staff have tried to accommodate individuals with significant behavioral issues, but found that the demands were excessive, as two staff members needed to be with them at all times and they posed a risk to staff and other clients. They will connect individuals who are unsuited to the program with other supports (i.e., CLSD, if they meet the criteria) but “the range of supports for these individuals is limited. This is a gap in services in the community. The individuals that we have been unable to support in the program should be in lifelong residential programs such as those provided by Ehrlo, but we are unable to connect them due to the referral and funding processes.”

The location of the program within the Community Clinic is seen as both an advantage (because of the ease of connecting clients with the other services offered there; see “Strengths” below) and a disadvantage (because of the ‘medicalized’ and institutional feel of the space). One partner agency representative felt that older youth in particular are often turned off by the clinical setting and would prefer a space that is more “youth-friendly.” In addition, some individuals may be confused by the layout and signage in the building and have difficulty finding the program facilities. Staff acknowledged that it would be preferable if the program could be directly accessed from the street.

Retention: Retention is not seen as an issue by staff so much as maintaining contact with clients because of their transience: many have unstable housing and both phone numbers and addresses may change frequently. Staff attempt to track clients down when they stop coming by checking in with other agencies that serve their clients, but it is often difficult to locate them. Clients may also stop attending the program because they are in custody (but at least then they can be more easily located).

4.5.4 Strengths

While there are individuals with FASD for whom this program is not suitable, as noted above, it works very well for others. The clients we interviewed had trouble articulating what they do in the program, but all spoke very positively about their experience, unanimously stating that they enjoy the program and could not suggest ways in which it could be improved. The representative of a partner agency that works closely with the program also has a very high opinion of it: “They’re absolutely beneficial and are awesome. I’m really happy with the services. They build good relationships with the clients.”

Flexible, client-directed, no attendance requirements: The program’s capacity to respond to each client’s needs, flexibly and comprehensively, was noted by many of those we interviewed. As a staff member commented, clients can get one-on-one support, participate in group programming, or simply ‘hang out’ in the activity room, depending on “the needs and abilities of each client each day.” The parent of a client appreciates the fact that “they shape their programs around the clients” rather than offering “one-size-fits-all services,” as other service providers do.

The flexibility around attendance is seen as a strength by a partner agency representative who sometimes refers clients to the program; other life skills programs that require regular attendance don’t work well for many people with FASD because the instability of their lives and the nature of their cognitive disability make it difficult for them to participate consistently. The RCC is seen as an “open arms” program where clients are made welcome whenever they come, without pressure to attend regularly.

Another partner agency representative expressed appreciation for the variety and comprehensiveness of the help the program is able to provide. “They do everything from making sure the guys get their taxes done . . . to trying to find funding. They keep track of their meds and doctors’ appointments. They work on hygiene and exercise.” A client put it this way: “What I like about here is, if I’m hungry, I can come eat here. If I’m bored, I can just come here and relax. If I’m tired, I can just come and have a nap.”

Safe space to hang out, offer mutual support, inclusion: The program provides clients with a place where they feel comfortable and welcomed and can engage in positive activities. As a staff member said, “We are very focused upon the need for community for disenfranchised citizens. The one thing about having a physical space is that people have a physical place to belong to, where they are accepted.” This is especially important because often individuals with FASD have nowhere else where they feel this sense of acceptance; as a partner agency representative explained, “sometimes these people are isolating themselves all day.” Another staff member stated, “There’s nowhere that they fit, really, so having something like this, they have somewhere to go. And I’ve heard a few clients say coming here they feel most normal. They don’t have to explain themselves. . . [A client said] ‘No one judges us and . . . we can just come here.’ This guy is a rugged, rugged guy, . . . kind of

a street guy and he just seemed really at peace here.” In the words of a client, “I have FASD so I wanted to fit in with a group . . . with my own, like to feel comfortable to come out hang and get away from stress away at home.”

In addition to providing a sense of acceptance and inclusion, the program helps clients by providing them with the opportunity to engage in positive activities, as one staff member explained: “I think it keeps a lot of our clients out of trouble, just by being able to come here and hang out instead of going and doing something that they shouldn’t.” A client commented, “I can come and chill out for a bit, instead of being at home and playing on my game system all day.”

Another dimension of the program is the opportunity provided in the group activities and activity room for clients to support each other, as a staff member explained: “One of the positive aspects of the program is that they help each other as best they can and are very kind to one another.”

At the heart of this supportive and welcoming environment is the respect and caring that staff members demonstrate to clients, as reflected in this comment: “The best parts of the job would be watching clients figure things out and realize that we’re a safe place for them to be and ... actually the clients are the absolute best part.”

Knowledgeable and experienced staff: The Clinic, with ten years of experience providing services to individuals with FASD, is recognized as an outstanding source of information and care in this field within the community. The parent of a long-standing client stated that “the RCC has been like a lifeline to me personally in keeping my sanity . . . It’s been absolutely invaluable.” This person and representatives of partner agencies commended program staff, particularly the program manager, for their high level of knowledge and expertise in the area of FASD: “They have done an amazing job of having very talented and clever and educated and qualified staff.” The program manager was singled out for her “personal qualities,” her understanding of FASD, and her helpfulness: “She’s always been amazing at being able to think about how to provide some service that would help to meet the need [of the client]. . . . In terms of the services provided by [the program manager] those have been absolutely amazing, outstanding, and certainly at the highest level of anything that has been offered for [client].” The partner agencies also mentioned the value of the program manager’s knowledge base and ability to educate others on FASD, stating that the training she provided to their staff “was amazingly helpful. It was great.” The design of the program, e.g., its flexibility and focus on meeting clients’ needs, reflects a solid understanding of how FASD affects individuals.

Presence of other services in the Clinic: Having other services in the Clinic, like exercise facilities and medical care, is a strength of this particular program because of the ease of access and greater coordination. This was noted by staff members and the parent of a client. “I think the exercise program is really big for [clients] because a lot of them are fairly unhealthy. If they didn’t come here . . . they wouldn’t be going and getting exercise and going to the gym.” Some of the clients also

mentioned obtaining health care and nutritional advice and using the exercise facilities. However, the downside of the Clinic, as noted earlier, is that it has a “little bit of an institutional feel to it,” in the words of client’s parent.

Collaboration with Probation Services: The close relationship between Probation Services and the program appears to be a very good fit, noted by both the program staff and the probation officer we interviewed, who commented that “it would be ridiculous not to send” any client who is suited to the program. Program staff “have good connections and they actually have a better knowledge of the resources in the city than I do. . . . and . . . they can get a lot more accomplished in a shorter time with the guys than I would ever be able to.” This individual spoke very highly of the impact the program has with probation clients: “I think it’s imperative that we have the FASD clinic. . . . In terms of probation this is an important program. I would really, really hate to see this program go.”

4.5.5 Challenges

Nature of clients’ disability: The barriers to participation noted earlier—such as transience, lack of support, and limited cognitive capacity—affect the attendance of those enrolled in the program, as a staff member explained: “For people with FASD, unless they have additional supports in the community, we cannot reasonably expect ‘regular’ attendance. . . . FASD is a complex brain based disability, and some people do not remember what day or time it is, that the program is running, or where it is. Others have such high levels of ADHD that they may intend to come to the program but within a minute are distracted and don’t make it. . . . There are issues around transportation (continually lose bus passes) and communication (lose their phones or run out of minutes) and transiency (last known address). We do provide transportation, but we need to connect with them in order to help them attend the program.”

As the parent of a client explained, individuals with FASD need to have repeated instruction. “[Clients] need, like, 25 exposures to opening the cookbook and following the recipe with someone at [their] shoulder and then maybe the 26th time [they] can do it [themselves]. So some of the services need to be offered again next year and again the year after that, and again the year after that, and again the year after that.”

Funding constraints, leading to staff turnover: This program is funded by the Regina Qu’Appelle Health Region. The year-to-year nature of this funding has created uncertainty and a lack of continuity, and the amount provided is insufficient to attract and retain excellent staff, resulting in a high level of turnover.

Having to re-apply for funding annually takes time and creates more work, not only in terms of the application itself, but because staff have to be hired and trained and clients recruited and enrolled each time the program is funded again. The short-term funding, combined with relatively low pay and lack of benefits, makes it difficult to attract and keep staff. Understaffing means that the

program manager has to spend more time with clients herself, with less time for administration, publicity, and networking. As the parent of a client commented, “one of the worst things is that the RCC is always, always, always trying to go after funding so that they can run some programs, and it would be so wonderful if they could have some steady funding that they could count on so that they could spend their time in delivering services which they’re so good at doing, as opposed to having to spend their time trying to raise money to be able to maintain some level of services.”

The turnover in staff has a negative impact on the clients. Staff commented that clients keep asking them if they’re going to be there tomorrow, and one explained, “It’s hard for them to make that connection with staff because they’re almost like, ‘Why bother, you’re going to be gone anyways.’ So that’s definitely a weakness.” One of the few critical comments made by a client referred to this issue: “So many new faces, though; that’s the only thing I’ve noticed.” The parent of a client thinks reducing turnover through increased funding and higher salaries is important “because building the trust and being able to maintain a program for twelve months instead of only for six or nine months is really critical to delivering services to the clients.”

This individual went on to say, “My experience is that various support programs seem to be contracted by the government because the government can get them to supply the services cheaper than if they have government staff who have a union and wage scale, and so as a result there’s a huge amount of turnover.”

Need for more one-on-one support: One partner agency representative and the parent of a client would like the program to be able to offer more one-on-one support, like that provided in mentorship programs, while recognizing that this would require additional funding. The parent explained that “the one-on-one mentoring seems to help the most. It’s about trust,” indicating that individual support is essential for the client’s “mental wellbeing” and to enable the client to benefit from the group activities. The parent wishes that staff could take clients out in the community and do more social activities, creating “a milieu where they could mix socially and develop true social skills,” which are often a deficit for people with FASD.

Similarly, the representative of one of the partner agencies we interviewed has found that the program has not worked well for most of the clients referred because they do not do well in groups. This individual would also like the program to be able to offer more individual direction and support. “It would just be nice if they had capacity to get more into that mentorship rather than the groups because a lot of my kids get turned off by the concept of going to a group.” None of the youth this person has referred to the program continue with the group. “A couple said that they just don’t want to be part of a group. I’ve had others say they didn’t feel like they were learning anything. And then others, they were just too involved in their addictions and too chaotic to show up.” Another client felt she was going to too many groups; what she wanted was “one support person to help with her independent living skills, help her with her parenting stuff, help her with her grocery shopping, help her with issues around her boyfriend and the abusive relationships” rather

than a compartmentalized approach in which she is told, “You need to go here for this and there for that.” “She said that she would be spending her life in groups morning, afternoon and evening,” and having to re-tell her story to each of the groups, which she found difficult.

This individual sees a need in general for more individual support staff who could be available on call, rather than relying on mobile crisis, where clients speak to a different person every time. The clients this person works with often have questions that they don’t know who to ask, and are reluctant to call someone they don’t know.

Lack of support during evenings and weekends: The parent of a client felt that providing services only during business hours on weekdays is a significant limitation, because evenings and weekends are when individuals are most likely to engage in negative behavior. Staff concurred: “There are not enough places for our clients to be. We’re a safe place. But when they leave here after a couple of hours they are going home to . . . whatever. The challenges are we can’t provide evening or weekend supports, which are critical times. Holidays have all our staff nervous . . . We know the risks that’s out there so . . . I wish we could do more.” One of the partner agency representatives also feels there is a great need for support outside business hours, and noted that this is a problem faced by all support programs.

Lack of external resources: Many individuals with FASD have difficulty finding and keeping employment because of their disability. As well, many come from low-income families that face multiple challenges. As a result, the clients seen by this program are dealing with poverty and all the additional stresses that it creates in a society which does not provide adequate support for people on low incomes, on top of their disability.

Staff identified the lack of resources for individuals with FASD as one of the biggest challenges they face. One commented that “a lot of [people with FASD] just slip through the cracks,” and another said, “We have to . . . accept that most individuals do not have enough support, period. We have to accept that FASD is a complex lifelong disability, and that some of what clients need for supports is not available. It is difficult to maintain clients when they are homeless, hungry and in need of basic care.” The partner agency representatives also commented on the inadequacy of appropriate housing for people with disabilities like FASD as a major problem: “Maintaining housing is incredibly difficult.”

A related issue noted by some of the individuals we interviewed is a need for more education around FASD in other sectors, such as health care and justice, so that people with FASD receive more appropriate care and treatment. One partner agency representative mentioned that this is another area in which the program manager has been helpful, by consulting with health care providers when problems arise with mutual clients.

4.5.6 Program impact

Clients had difficulty articulating the impact the program has had on them but most indicated that there had been some positive effects. These included lifestyle changes, such as “working out twice a week and walking almost every day” and eating and sleeping better, as well as emotional: “Before, I couldn’t really talk to anybody. I always have to keep my emotions and my anger and everything and nowadays [since I] have been coming here, [I’m] sort of opening up and learning how to talk about them.” Also, as mentioned under ‘program strengths,’ several clients indicated that the program gives them a place to spend time, to have something to eat, socialize, get help and engage in positive activities, which is better than what they would be doing otherwise. One client said, “I am less shy now, getting to know everybody here.” Before attending the program, “I was at home all the time. . . It’s nice to get away from the home and stress.” Another said, “Medically it’s helped me a lot . . . Before I don’t know where to go to or who to turn to for help.”

As a staff member explained, much of what the program accomplishes consists of *preventing* bad outcomes, which by its nature is difficult to measure: “Success for many of our clients means they haven’t been arrested, beaten, robbed, abused, or drunk every day.” The parent of a client commented that the nature of FASD means that individuals experience frequent crises; simply decreasing the frequency of these crises is an improvement: “The better-trained staff and the more that they can stay in place, what happens is that the time between the crises expands. So in other words [the client] has the crisis every six weeks instead of every two weeks which makes a huge improvement in the quality of life.”

One of the partner agency representatives gave the example of a client who the staff noticed was involved in “really risky, potentially dangerous situations.” With the help of the police and the client’s agreement, he was able to be monitored in the community for his own safety and to prevent him from committing an offence. “So that’s something that couldn’t have happened if he wasn’t at the clinic and Probation was not attached and people were not keeping an eye out for this guy.”

Staff were able to cite some specific cases in which clients achieved observable improvements. For example, “We have had clients who are completing their probation orders, and thanks to a combination of supports (the probation worker and our program) have been able to find the support needed to problem solve and have not re-offended, breaking a cycle that may have been years old.”

One of the partner agency representatives mentioned a client who attends the program who “came from a really abusive family, lots of high-risk behaviours, lots of boundary issues. Because he’s been going there for almost two years now—because he’s now developed those safe trusting relationships with their staff, when something comes up with family or finances or any sort of crisis,

they're his support people so they know about it pretty much right away. So the impact is that . . . the client has support that they never had before. "

Connecting clients with other sources of support and care, such as SAID/SAP and SSILC or SAC, is an important aspect of this program and one where there have been numerous successes. Co-existing health conditions have been identified and clients' adherence to medications and dietary regimes monitored; individuals who want assessments are able to get them, albeit slowly; and some clients have been helped to find housing and to set up savings accounts.

4.5.7 Increasing effectiveness

Staff mentioned numerous ways in which they would like to be able to expand their services, such as increasing their physical space so that they could offer more basic life skills training (i.e., laundry and cooking), increasing funding so as to offer more resources outside regular business hours and providing more varied group activities, and providing "smoother access" to adult diagnosis by having a psychologist onsite. Enhanced coordination of services would also be beneficial, e.g., by having better communication amongst all the individuals working with each client.

The staff's desire to offer expanded services was echoed by partner agency representatives. The physician in the Clinic would also like to see the program expanded, as well as having more physicians able to diagnose FASD, to keep up with the demand. Like others we interviewed, he sees a need for more supports for adults with FASD—up until the age of 18 there is better support, but after that, "they're left swimming." Related to this is a need for increased understanding of the lifelong nature of FASD: "I think that's the lack of knowledge, there's been ideas that people who are cognitively impaired, when they reach 18 will get better. They don't." The parent of a client reiterated the fact that people with FASD need support for their whole lives: "I just hope the outcome of the research will help the government understand that the need of these clients is ongoing. . . . [The client's] needs aren't going to go away . . . I don't know any way that's going to be achieved without government-funded support." This individual commended the current Minister of Social Services for the efforts she has made to learn about FASD.

Similarly, the other partner agency representatives see the Clinic as offering valuable services, with room to do more: "I think the Community Clinic does really well with the time and the money that they have and it would be nice if they had an opportunity to expand what they are able to do. . . . They can only do so much with the funding that they have and so a lot of is [the program manager] saying it's not that they don't want to do it, it's that they physically don't have the staffing to do it."

5.0 Discussion and Conclusions

The CDS and four other programs we examined are clearly addressing an important and previously unmet need for support among individuals with cognitive disabilities. These programs enhance the

quality of life and promote social inclusion for some of the most marginalized individuals in our province, as well as decreasing the stress experienced by the families and caregivers of these individuals and potentially preventing a variety of negative outcomes. They accomplish this through the efforts of knowledgeable and compassionate staff who work to build close relationships with other agencies and organizations.

Recruiting and retaining clients is not an issue for any of the programs; rather, the difficulty is in meeting the demands for support with the current level of funding. We do not have the data needed to determine the number of eligible individuals and families who are not involved in these programs, but we found a consensus amongst those we interviewed that there are many more people with cognitive disabilities than the current clientele.

Given the lifelong nature of these disabilities and the difficulty of preventing them, the demand for community-based support programs is likely to only increase with time, as they become better known and the target population grows. Several evaluation participants mentioned that Saskatoon's mental health court, which had its first sitting in November 2013, will increase the need for exactly the kinds of supports offered by these programs. Indeed, the number of clients involved in CDS has risen sharply over the past seven years, and neither CUMFI's Wellness Centre nor the FASD Support Network's Family Support Program was able to accept new clients at the time of this evaluation. We found widespread agreement that all these programs, including CDS, need to be expanded in order to better meet the need for support in the target population.

Evaluation participants described several ways in which expansion could occur: increasing the number of staff in existing programs as well as adding new programs run by other organizations; expanding the coverage of community-based support programs outside Saskatoon and Regina to other regions of the province; increasing funding of programs in order to attract and retain well qualified and experienced staff and offer them competitive salaries and benefits for the stressful and demanding work they do (and for the Regina Community Clinic, providing longer-term funding); and enabling existing programs to expand their offerings and hours. In addition, the need for better access to assessment and diagnosis, especially for adults, was mentioned many times.

While our evaluation could not quantify the benefits produced by the programs, there is good reason to believe that they could result in substantial cost savings, as several evaluation participants mentioned, by keeping clients out of jails, hospitals, and emergency rooms. Supporting healthy pregnancies and parenting would have additional benefits and is especially relevant for the FASD population.

Evaluation participants had few suggestions for improving the community-based programs other than expanding them. On the other hand, there seems to be considerable room for improvement in CDS. This includes expansion (i.e., increasing the number of consultants and the amount of funding)

but also a range of other measures: standardizing CDS across regions, simplifying and speeding up the application, claim submission and renewal processes, improving communication and transparency, loosening up some funding limitations, including updating the income cut-offs and funding amounts, clarifying the roles and relationships of the various team members, enhancing access to services for clients outside Saskatoon and Regina, and making it easier for clients to find qualified mentors. Some evaluation participants mentioned the need for more services for adults and the difficulty of engaging individuals with FASD, which speak to the value of the community-based support programs that are designed for these very purposes.

Not surprisingly, the shortcomings of CDS documented here are very similar to those identified in the 'Cognitive Disability Consultant Review' prepared by the CDS Coordinator in October 2013. Of greater concern is the fact that many of the same issues were described in the 2007 'Cognitive Disability Strategy Process Evaluation' of the first four CDS sites, such as the onerous, time-consuming paperwork, lag times, poor communication, excessive administrative work for CDCs, inconsistencies across regions, insufficient funding, confusion around roles and responsibilities, and inadequate supply of mentors.

Across all programs, we heard about the need for broader education and training, to reduce the stigma associated with cognitive disabilities in the general population and to increase the capacity of the human services system to meet the needs of individuals with cognitive disabilities. The programs we evaluated work towards this latter objective in their interactions with a wide variety of other agencies and organizations, but additional efforts would be of benefit, ultimately contributing to greater inclusion of these individuals in society and the development of natural communities which could provide them with ongoing support.

Many of the clients of these programs live in poverty, which compounds the difficulties they face due to their disability or that of their child. Evaluation participants commented on the lack of external resources for their clients that increases their burden, most notably access to healthy food and appropriate housing.

Our evaluation has several limitations that must be acknowledged. While we interviewed a large number of individuals overall, the number of clients per program was relatively low, due to funding and time constraints. Moreover, the clients with cognitive disabilities were limited in their capacity to answer our questions thoughtfully and accurately. Some of the staff we interviewed had only recently started working in the programs (related to the high levels of staff turnover at most of the community-based organizations which we noted) and therefore had little experience on which to reflect. Finally, there may be some bias in relying as heavily as this evaluation does on the perceptions of program staff to assess how well the programs are working and their impact on clients. However, we did not find much discrepancy between their views and those of the partner agency representatives or service providers, most of whom have no stake in the programs.

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RESEARCH QUESTIONS	Program Administrators	Mentors/coaches	Clients	Partner Agencies
<p>1. REACH</p> <p>1.1 What is the overall percentage of the target population served by the program? (subject to availability of data)</p> <p>1.2 What is the distribution of the client population served in terms of age, gender, Aboriginal status, family, employment, and housing status?</p> <p>1.3 What is the distribution of waitlisted clients?</p> <p>1.4 What is the “trajectory” of program engagement of the clients served?</p> <p>1.5 Has the programs shown an increase in its reach to the target population? Does statistics show any trend in program reach?</p> <p>1.6 What steps have program administrators taken to increase the program utilization by the target population? Are they effective?</p>	<p>Have you taken any steps to try to increase the uptake of your program? If so, please describe.</p> <p>How effective do you think they have been?</p> <p>What are the challenges to increasing the reach of your program into the target population? Any ideas for overcoming them?</p>	<p>How do you help spread awareness about FASD and your services in the community?</p> <p>How effective do you think these activities are?</p> <p>What do you think could be done to reach more people?</p>	<p>Have you recommended the program to anybody?</p> <p>Do you think it would help others you know who have FASD?</p> <p>Do you know of people with FASD who aren’t involved in this program?</p> <p>What do you think are the reasons they’re not involved?</p>	<p>Are you aware of people with FASD who are not involved in this program?</p> <p>What are the barriers to them getting involved?</p> <p>Do you have any thoughts on how this might be improved?</p>
<p>2. IMPLEMENTATION</p> <p>2.1 Program delivery</p> <p>2.1.1 What models of program delivery have been adopted? What is the perception of the program administrators of the delivery methodologies?</p> <p>2.1.2 What are the perceptions of the clients in terms of program delivery?</p> <p>2.1.3 How do the mentors perceive their caseloads and adequacy of time?</p> <p>2.1.4 Is the program delivered in the same manner as initially intended or planned? If changes have been made, what was the reason?</p> <p>2.1.5 What are the administrative and technical challenges faced?</p> <p>2.1.6 How is the program progressing in terms of partnerships and collaborations with other agencies?</p>	<p>What models do you use for program delivery? How well do you think they are working?</p> <p>Is the program delivered in the same manner as initially intended or planned? If not, what changes were made and why?</p> <p>What, if any, administrative and technical challenges have you experienced?</p> <p>How is the program progressing in terms of partnerships and collaborations with other agencies?</p>	<p>Can you tell me how long you have been working for this organization? What attracted you to this job?</p> <p>What are the best parts of the work you do? What are the hardest?</p> <p>What kind of work or training had you done before you started in this position?</p> <p>What kind of training did you receive from the organization? Is there additional training that you’d like to get that would help you do your job better?</p> <p>How many clients do you currently have? Has this changed over time? What do you think is the ideal number?</p>	<p>What activities have you taken part in?</p> <p>Which do you like best? What do you like about them?</p> <p>Which don’t you like as much? What is it you don’t like? Is there anything that would make you like these activities more?</p> <p>How often do you meet up with your coach/mentor? Do you ever have trouble reaching your coach/mentor? What kinds of things do you like doing with your coach/mentor?</p> <p>Have you been referred to any other services by your coach/mentor? If so what are they?</p>	<p>How long has your agency been associated with this program?</p> <p>How often do you refer clients to this program? Do you refer clients to any other programs? If so, how do you decide where to refer clients?</p> <p>Are there other ways in which you interact with the organization, other than referring clients? Can you tell me about how this works?</p> <p>Do you have any concerns about your relationship with the organization, e.g., regarding communication, coordination of services, etc.?</p>

		<p>How often do you see clients, and how much time do you spend with them? What influences this? Would you like it to be different in any way?</p> <p>What do you do with clients? (Group and individual activities) How do you decide what to do? Which activities are most popular with clients?</p> <p>What challenges do you face in doing your job? What kind of support do you get from your organization in meeting these challenges?</p>	<p>What other services do you wish were included in the program?</p> <p>Has your coach/mentor helped you get funding from CDS?</p>	<p>Have you taken part in any educational or training sessions offered by this program? If so, how helpful would you say they were?</p> <p>What is your opinion of the services provided by this program?</p>
<p>2.2 Program uptake</p> <p>2.2.1 What is the level of interest that the clients express in uptake of the program?</p> <p>2.2.2 What are the perceptions of mentors about program uptake by clients?</p> <p>2.2.3 What are the challenges faced in client retention?</p> <p>2.2.4 What are the strategies that have proved successful in client attendance and retention?</p>	<p>What challenges do you face in client retention? What strategies have you tried to address these issues, and how effective have they been?</p>	<p>How much interest would you say clients have in this program? How well is it meeting their needs? What could make it better?</p> <p>It seems that clients can be involved in the program at different levels—some are regular attenders, others you see once in a while, some have been coming for a long time, others come and go. Can you tell me more about this?</p> <p>Is client dropout much of a problem? What do you think can be done about this?</p> <p>What is your opinion of the assessment service offered by the program (if applicable)? Its effectiveness in planning case management?</p>	<p>How long have you been coming to this program?</p> <p>How did you get to know about the program?</p> <p>What interested you about the program and made you want to come?</p> <p>Do you think you'll keep coming to the program? Are there things that make it hard to keep coming? Can you think of anything that could be done to make it easier for you to be part of the program?</p>	
<p>3. EFFECTIVENESS</p> <p><i>The concept of the medicine wheel will be used where appropriate to guide questions about the program's impact on clients' wellbeing.</i></p> <p>3.1 Physical (including lifestyle and addictions)</p> <p>3.1.1 What impact has the program had on clients' lifestyle, physical health and living conditions?</p>		<p>Thinking about the impact this program has had on clients, can you give me some specific examples of changes you've seen? (Prompt for physical/lifestyle, mental, emotional/social, spiritual health, financial/practical situation, help with addictions.)</p> <p>Which activities do you think are most effective?</p>	<p>How has your coach/mentor helped you be healthier? What other kinds of help would you like to get to improve your health in general?</p> <p>(If appropriate, showing the Medicine Wheel graphic: physical, mental, emotional, and spiritual aspects of wellbeing)</p>	<p>What kind of feedback have you received from clients about this program?</p> <p>Do you have any sense of the impact the program is having on the client population?</p>

<p>3.2 Mental</p> <p>3.2.1 What impact has the program had on clients' mental functioning?</p> <p>3.3 Emotional (including social)</p> <p>3.3.1 What impact has the program had on clients' emotional wellbeing and relationships?</p> <p>3.4 Spiritual</p> <p>3.4.1 What impact has the program had on clients' spiritual wellbeing?</p> <p>3.4.2 Is the program perceived to be culturally appropriate by Aboriginal clients?</p>		<p>Is there anything you can suggest that would make it easier for you to help clients more?</p>	<p>Can you tell me about some changes in your physical health that have happened since you've been part of this program? For example, have you been eating better? Playing sports or going to the gym? Smoking less? Do you need to go to the doctor or hospital less often? Have you got any help for addictions?</p> <p>Has your living situation changed since you've been part of the program, e.g., have you gotten into better housing, do you have more of a routine, have you had any paid work?</p> <p>What about your mental health? Has your coach helped you make plans and follow them? Are you better at remembering things you are supposed to do? Do you think you make better decisions now?</p> <p>How about your emotional health? Do you talk to your coach about your problems? Has your coach helped you get counseling? How has that been for you? Have you met new people through the program? How has that helped you? Are your relationships with family and friends different since you've been coming to the program?</p> <p>Would you say the program has had any effects on your spiritual wellbeing? Can you tell me about this? (As an Aboriginal person, do you think the program is a good fit for you? In what ways?)</p> <p>Overall, what difference would you say being part of this program has made in your day-to-day life? Can you give me some examples of how things were for you before, and how they are now?</p>	
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<p>4. SUSTAINABILITY AND IMPROVEMENTS</p> <p>4.1 What are the pros and cons of the program as seen by clients, partners, mentors, administrative personnel?</p> <p>4.2 What are the challenges foreseen in terms of sustainability of the program?</p> <p>4.3 What are the suggestions to expand the scope of the program to make it more acceptable and effective?</p>	<p>Overall, what do you think are the biggest strengths and weaknesses of this program?</p> <p>What, if anything, would you like to see changed about it?</p>	<p>Overall, what do you think are the biggest strengths and weaknesses of this program?</p> <p>What, if anything, would you like to see changed about it?</p>		<p>Do you have any suggestions for improvement in terms of services for people with FASD, related specifically to this program? In general?</p>
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Prepared by Nazeem Muhajarine, SPHERU, University of Saskatchewan

September 3, 2013

B.1: Letter of Invitation for Clients



SASKATCHEWAN POPULATION HEALTH AND EVALUATION RESEARCH UNIT

University of Saskatchewan, 501 - 121 Research Drive
Saskatoon, SK S7N 1K2
(306) 966-2250 (tel), (306) 966-6487 (fax)
Email: spheru@usask.ca

{Insert date}

Dear **{insert participant name}**,

I am writing to ask for your help in a research project. We would like to ask you some questions about the mentor services that you get at {insert organization name}. What you tell us will help {insert organization name} improve these services. Everyone who gets mentor services from {insert organization name} can be part of this project.

Here is what we would like from you. One of our researchers will come to {insert organization name} and ask you some questions for about half an hour. If you want, your mentor will be in the room with you. It is up to you whether or not you want to take part in this project. It will not make any difference to how you are treated or the services you get from {insert organization name}. If you say you want to be interviewed, you can change your mind later. And when you are being interviewed, you don't have to answer any of the questions you don't want to. You will not be given anything for taking part in this interview.

Everything you say will be kept private. We will not use your name on any of the information you give us.

If you would like to be interviewed, please tell your mentor/coach/support worker. We will find a day and time when we can meet with you.

If you have any questions, please contact me at the phone number or e-mail address below.

Thank you.

Sincerely,
Dr. Nazeem Muhajarine
Professor and Chair, Community Health and Epidemiology,
College of Medicine, University of Saskatchewan,
Director, Saskatchewan Population Health and Evaluation Research Unit (SPHERU)
Phone: 306-966-7940; Email: nazeem.muhajarine@usask.ca

B.2: Letter of Invitation for All Other Participants



SASKATCHEWAN POPULATION HEALTH AND EVALUATION RESEARCH UNIT

University of Saskatchewan, 501 - 121 Research Drive
Saskatoon, SK S7N 1K2
(306) 966-2250 (tel), (306) 966-6487 (fax)
Email: spheru@usask.ca

{insert date}

Dear {insert name},

I am writing to invite you to participate in a research study to evaluate {insert name of program and organization}. Through this evaluation we hope to collect information that would help improve the services offered by the {insert name of program and organization} and the Ministry of Health. This study is funded by the Ministry of Health, Government of Saskatchewan and has been approved by the Research Ethics Boards at the University of Saskatchewan. All {insert name of role} are eligible to participate.

If you agree to participate, you will be asked to take part in an {interview/focus group} conducted by our researchers. The duration of this {interview/focus group} will be about {insert time}. **The interview can take place at a date and time convenient to you.**

Your participation in this interview is voluntary and, further, you may answer only those questions that you are comfortable with. Whether you choose to participate or not will have no effect on your employment, services you provide or how you will be treated. You have the right to withdraw from the study at any time. No compensation will be provided to you for taking part in this study. All data collected will be kept confidential in the offices of the Saskatchewan Population Health and Evaluation Research Unit offices and will not be shared with anyone. The principal investigator and only those who need access to the data for analysis will be given access to the data. Names and identifiers will not be associated with any of the data.

If you would like to participate please confirm with Duvaraga Sivajohanathan, project coordinator, at duvaraga.sivajohanathan@usask.ca. If you have any further questions about this study feel free to contact me. Thank you for your anticipated participation.

Sincerely,

Dr. Nazeem Muhajarine
Professor and Chair, Community Health and Epidemiology,
College of Medicine, University of Saskatchewan,
Director, Saskatchewan Population Health and Evaluation Research Unit (SPHERU)
Phone: 306 966 7940; Email: nazeem.muhajarine@usask.ca

C.1: Consent Form for Clients



SASKATCHEWAN POPULATION HEALTH AND EVALUATION RESEARCH UNIT

University of Saskatchewan, 501 - 121 Research Drive
Saskatoon, SK S7N 1K2
(306) 966-2250
(306) 966-6487 (fax)
Email: spheru@usask.ca

Evaluation of Cognitive Disability Strategy services funded by Ministry of Health, Government of Saskatchewan

The Ministry of Health wants to know how useful the programs it pays for are. One of these programs is {name of program}. We want to find out what people like you who are part of this program think of it. By sharing your views, you can help make these programs better.

It is up to you whether you take part or not. If you don't want to, nothing bad will happen. If you say 'yes,' I will ask you questions about this program and what it is like for you. Your {mentor/coach} will be here with us. But you can ask him or her to leave at any time if you want. You don't have to answer any of the questions that you don't want to. You can stop the interview at any time. There are no risks or benefits to you by taking part. You will not be given anything in return for answering our questions.

The questions will take about half an hour. I will record the interview so that I will be sure to get everything you say. What you tell me will be kept private. We will not use your name or any other information that tells people who you are. Do you have any questions about this project? If you have a question later please contact Dr. Nazeem Muhajarine, the leader of the project, by phone (306-966-7940) or email (nazeem.muhajarine@usask.ca) or mail (address at the top of this page). If you would like to have a copy of the final report of this project, ask Dr. Muhajarine for one.

The University of Saskatchewan Research Ethics Board has given its okay to this research project on ethical grounds. If you have any questions about your rights as a participant, call or email the Research Ethics Office (ethics.office@usask.ca, 306-966-2975 or toll free 888-966-2975).

By signing this, you are saying:

- you understand what I have just told you
• you have had the chance to ask questions and your questions have been answered
• you know that you can change your mind about being part of the project
• you are okay with having your interview recorded
• you want to take part in this project.

Name of Participant

Signature

Date

Researcher's Signature

Date

A copy of this form will be left with you, and a copy will be taken by the researcher.

C.2: Consent Form for All Other Participants



SASKATCHEWAN POPULATION HEALTH AND EVALUATION RESEARCH UNIT

University of Saskatchewan, 501 - 121 Research Drive

Saskatoon, SK S7N 1K2

(306) 966-2250 (tel), (306) 966-6487 (fax)

Email: spheru@usask.ca

Evaluation of Cognitive Disability Strategy services funded by Ministry of Health, Government of Saskatchewan

Researcher

Nazeem Muhajarine, PhD

Professor and Chair, Community Health and Epidemiology,

College of Medicine, University of Saskatchewan,

Director, Saskatchewan Population Health and Evaluation Research Unit (SPHERU)

Phone: 306-966-7940

E-mail: nazeem.muhajarine@usask.ca

Supervisor

Kathryn Green, ScD

Researcher, University of Saskatchewan

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Shankar babu Chelladurai, MPH (c)

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Phone: 306-966-2693

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Stacey McHenry, MPH

Department of Psychology

University of Saskatchewan

Email: stacey.mchenry@usask.ca

Purpose of the Research

This project evaluates the Government of Saskatchewan's Cognitive Disability Strategy (CDS), which aims to improve the quality of life for people with cognitive disabilities. Funding is provided under the CDS to community-based organizations and several consultants across the province to help people with cognitive disabilities, including FASD. We are working with four community-based organizations (FASD Support Network, Central Urban Métis Federation Inc., Regina Community Clinic, and Aboriginal Family Services Centre) and the CDS consultants to find out how well the services and programs they provide are functioning. This evaluation will help understand the CDS strategy overall as well as the four individual programs. It will also identify strengths and weaknesses in the strategy and will help improve the strategy and the programs of the community-based organizations. The evaluation is being paid for by the Ministry of Health, Government of Saskatchewan.

Procedures

To carry out this evaluation, we are interviewing clients and support workers/mentors/coaches with FASD Support Network, Central Urban Métis Federation Inc., Regina Community Clinic and Aboriginal Family Services Centre, as well as some of the agencies they partner with, and the CDS consultants.

If you agree to participate, we will interview you in a {focus group or interview} along with the other {insert role} from {your organization} We will ask you questions about what you do, how well you think the program is working, the impact it has on clients, and how it could be improved. With your permission, the focus group will be audio recorded to make sure we have a complete record of what is said. One research assistant will ask the questions, while another takes notes. You have the right to withdraw from the study at any time, and you do not have to answer any of the questions you are asked.

Please feel free to ask any questions regarding the procedures and goals of the study or your role.

Potential Risks & Benefits

There are no known or anticipated risks to you by participating in this research.

There are no personal benefits to the participants in this study. By choosing to take part, you may help to improve services for people with cognitive disabilities in Saskatchewan. The information you share will help the Government of Saskatchewan assess the effectiveness of CDS services. This study will help researchers and the Government of Saskatchewan better understand the needs of people with cognitive disabilities such as FASD, which will allow better policies to be developed in the future. No payment will be provided to you for taking part in this interview.

Confidentiality

What you say will be kept confidential by the research team. Any information that might identify who you are will be removed before we share the findings in any form. Because this is a group interview, it is important that you do not share anything that is said during the interview with anyone outside the group. We cannot guarantee that other people in this focus group will keep what you say confidential.

At any time during the focus group, you have the right to ask that the recording device be turned off. The audio files from the focus group will be transcribed and, if requested, the written transcripts will be given to you. You may make any changes you wish to the transcript before approving it. You will give your approval by signing the transcript release form.

All identifying information (i.e., consent forms and master lists) will be stored separately from the data collected. All electronic files will be stored in password protected computer files. All hardcopy data (i.e., audio files and focus group transcripts) will be stored in a locked filing cabinet at SPHERU. Only the researchers (listed on page 1) will have access to these files. The master list and audio files will be destroyed when data collection is complete and they are no longer needed (in 5 years).

Right to Withdraw

Your participation is voluntary. You may choose to answer only those questions that you are comfortable with. You may withdraw from the project for any reason, at any time, without explanation or penalty of any sort. Whether you choose to participate or not will have no effect on how you will be treated.

Should you wish to withdraw, please contact the researchers (contact information can be found on page 1) and all your data will be deleted. Your right to withdraw data from the study will apply until the findings have been shared. After December 2013, it is possible that some findings may have been shared and it may not be possible to withdraw your data.

Questions or Concerns

If you have any questions or would like further information about this project before or after the focus group, you can contact Dr. Muhajarine (see page 1).

The University of Saskatchewan Research Ethics Board has approved this research project on ethical grounds. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office (ethics.office@usask.ca, (306) 966-2975 or toll free (888) 966-2975).

If you would like to get a copy of the project's findings, please contact Dr. Muhajarine (see page 1).

Consent

Your signature below indicates that you have read and understand the description provided.

I have read the information in this consent form.

I understand the purpose and procedures and the possible risks and benefits of the study.

I have had the chance to ask questions and my questions have been answered.

I understand that I am free to withdraw from this study at any time for any reason and the decision to stop taking part will not affect me.

I grant permission for my focus group session to be audio recorded.

I give permission to the use and disclosure of my de-identified information collected for the research purposes described in this form.

I consent to participate in the research project. A copy of this Consent Form has been given to me for my records.

Name of Participant

Signature

Date

Researcher's Signature

Date

A copy of this consent will be left with you, and a copy will be taken by the researcher.

Appendix D: Transcript Review Form



SASKATCHEWAN POPULATION HEALTH AND EVALUATION RESEARCH UNIT

University of Saskatchewan, 501 - 121 Research Drive
Saskatoon, SK S7N 1K2
(306) 966-2250
(306) 966-7920 (fax)
Email: spheru@usask.ca

TRANSCRIPT REVIEW FORM

Evaluation of Cognitive Disability Strategy services funded by Ministry of Health, Government of Saskatchewan

Thank you again for helping us with this project. If you have any questions about the ethics of the project please contact the University of Saskatchewan Behavioural Research Ethics Board at ethics.office@usask.ca or (306) 966-2975 (or toll free at (866) 966-2975).

By checking here, I am saying I do not need to see a copy of my interview in writing before it is used in the project.

By checking here, I am saying that I want to see a copy of my interview in writing before it is used in the project. If I want to make any changes to it, I know that I have only 14 days (two weeks) to do so. (Please give us a mailing address or e-mail address so that we can send it to you.)

Name of Participant

Date

Signature of Participant

Signature of researcher

Appendix E: Transcript Release Form



SASKATCHEWAN POPULATION HEALTH AND EVALUATION RESEARCH UNIT

University of Saskatchewan, 501 - 121 Research Drive
Saskatoon, SK S7N 1K2
(306) 966-2250 (tel), (306) 966-7920 (fax)
Email: spheru@usask.ca

TRANSCRIPT RELEASE FORM

Evaluation of Cognitive Disability Strategy services funded by Ministry of Health, Government of Saskatchewan

I, _____, have reviewed the complete transcript of my interview in this project, and have had the chance to add, change, or remove information from the transcript as I wish. I acknowledge that the transcript accurately reflects what I said in my interview. I hereby authorize the release of this transcript to Dr. Nazeem Muhajarine to be used as described in the Consent Form. I have received a copy of this Transcript Release Form for my own records.

Name of Participant

Date

Signature of Participant

Signature of Researcher

Appendix F: Focus Group and Interview Guides

F.1: Focus Group Guide for Mentors/Coaches/Family Support Workers

Introduction

- Introduce yourselves to participants.
- Explain Consent Form and Transcript Review (e.g., “The first thing I want to do is explain to you what this project is all about and what we are asking you to do, and to get your agreement to take part.”)
- Summarize the key points of the Consent Form and have participants read through it and the Transcript Review; answer any questions.
- Have participants sign Consent Form and Transcript Review.
- Briefly give an overview of the focus group (e.g., “I’ll start by finding out a bit about your background, then get some details about the program and your role in it. Next we’ll look at how you think the program impacts clients, and we’ll finish up by looking at how the program might be improved, its strengths and weaknesses. We’ll start by going around the table and getting you to introduce yourselves, but after that, you can just jump in when you have something to say—we don’t have to go in order. We do want to hear what each of you has to say, so we’ll try to make sure everyone has a chance to speak if they want to.”)

Background

“To start, I’d like to find out your background and how you came to be a mentor/coach/family support worker.”

Go around the room/table and ask each participant to introduce him/herself and say how long they have been working for this organization.

1. What attracted you to this job?
2. What are the best parts of the work you do? What are the hardest?
3. What kind of work or training had you done before you started in this position? What kind of training did you receive from the organization? Is there additional training that you’d like to get that would help you do your job better?

Program details

“So now I’d like to find out a bit more about your work with [this program].”

4. How many clients do you currently have? Has this changed over time? What do you think is the ideal number?
5. How often do you see clients, and how much time do you spend with them? What influences this? Would you like it to be different in any way?
6. What do you do with clients? (Group and individual activities) How do you decide what to do? Which activities are most popular with clients?

7. There is often new information that comes out on how to help people with cognitive disabilities. Can you think of any time when you changed what you do or new activities or services were added into the program, because of some new information?
8. How often do you interact with your partner agencies? Which ones do you have the most to do with? What are the different ways in which you interact?
9. How do you help spread awareness about FASD and your services in the community? How effective do you think these activities are?
10. [Family Support Network only] How do you help your clients secure CDS funding or access other resources? How well does that work?

Impact

“This next section is a really important one. It’s about the impact that the program has on clients.”

11. Thinking about the different clients you’ve worked with, how would you say the program has helped them? Can you give me some specific examples of changes you’ve seen in them during the time they’ve been with the program? [Prompt as needed for physical, mental, emotional/social, spiritual health, financial/practical situation, help with addictions.]

Evaluation

“Next we’d like to find out your opinion of how effective the different parts of the program are, and how they might be improved.”

12. Which activities do you think are most effective? Is there anything you can suggest that would make it easier for you to help clients more?
13. [CUMFI only] What is your opinion of the assessment service offered by the program? How helpful is it in planning case management?
14. What challenges do you face in doing your job? What kind of support do you get from your organization in meeting these challenges? How helpful is this support? How could it be better?
15. Do you see yourself staying with this job for a while? What would make you more likely to stay? Why do you think coaches/mentors leave?
16. What are the issues around client retention? Any suggestions for improving?
17. Overall, what do you think are the biggest strengths and weaknesses of this program? What, if anything, would you like to see changed about it?
18. That’s the end of my questions. Is there anything else that you think we should know about this program?

[Thank everyone for their participation. Remind them that ‘what’s said in this group, stays in the group.’]

F.2: Focus Group Guide for Cognitive Disability Strategy Consultants

Introduction

- Introduce yourselves to participants.
- Explain Consent Form and Transcript Review (e.g., “The first thing I want to do is explain to you what this project is all about and what we are asking you to do, and to get your agreement to take part.”)
- Summarize the key points of the Consent Form and have participants read through it and the Transcript Review; answer any questions.
- Have participants sign Consent Form and Transcript Review.
- Briefly give an overview of the focus group (e.g., “I’ll start by finding out a bit about your background, then get some details about your role as Cognitive Disability Consultant. Next we’ll look at how well the different components of the CDS are working and how they could be improved, and finally, how the CDS impacts clients. We’ll start by going around the table and getting you to introduce yourselves, but after that, you can just jump in when you have something to say—you don’t have to go in order. We do want to hear what each of you has to say, so we’ll try to make sure everyone has a chance to speak if they want to.”)

Background

“To start, we’d like to find out your background and how you came to be a consultant.”

1. Go around the room/table and ask each participant to introduce him/herself and say (1) how long they have been working as a CDS consultant, (2) the community in which they work, and (3) their host agency.
2. What is your background, in terms of education and work experience?
3. How well equipped to do your job as a consultant do you feel you are--is there additional training that you’d like to get that would help you do your job better?

Position Details

“Now we’d like to know a bit more about what you do in your role as a consultant.”

4. How many clients do you currently have? Has this changed over time? Would you say your caseload is manageable?
5. What are the most common diagnoses of your clients? Has this changed over time?
6. How do clients find out about the CDS? (e.g., referral from other agencies, self-referral) Do you think there’s a need to increase awareness about cognitive disabilities and your services in the community? If so, what would be the best way to do this? Are there particular groups of people who you think aren’t accessing the CDS who should be?
7. What support and supervision do you receive? Is this support and supervision meeting your needs?

8. Would you say that you have a clear understanding of the roles and responsibilities of your current position as a consultant?
9. Are there activities that you have been doing but that you feel are not, or shouldn't be a part of your job? (e.g., administrative duties; acting as case manager/team lead) Which activities take up most of your time? What would you like to be spending more time on? Less time on? [If not discussed: What kinds of behavioural support services do you offer clients?]

Evaluation

“Next, we'd like to hear your thoughts on how well different aspects of the CDS are working.”

10. What is your relationship with your host agency like?
11. What kinds of partnerships and collaborations with other agencies does the CDS have in your community? Can you give me some examples of partnerships that are working well, and some that aren't?
12. How well would you say the CDS links with other initiatives, like School Plus or KidsFirst? Is this a problem? What might help make these links stronger?
13. Overall, how well do you think the CDS is understood by others in your community? How do you think this could be improved?
14. What about communication with government agencies, and with the CDS staff in particular—how well is that working? How effective is your communication with the intake committee and provincial committee? How well do these committees function?
15. Now, thinking about the process for clients, from their initial contact with the CDS, through the assessment (i.e., Daily Living Skills Assessment/DLSA) and application process, to finding a mentor, getting funding, and accessing services—which parts would you say are working best in your community, and where are there problems? [Probes: Does the referral/request process work well? Is DLSA done in a timely fashion? Is it hard to find mentors? Are mentors adequately trained and supported? Is it hard to find a case manager? How easy is it for clients to apply for and receive appropriate funding? Are your clients able to access the services they need in the community?]
16. Have there been any times when a client you considered to be deserving didn't get CDS funding? (Can you tell me more about this?) Do you have any comments on the overall effectiveness of the CDS client approval process? What about the appeal process?

Impact

“Now I'd like to turn to the question of how well the CDS is helping clients.”

17. Thinking about the impact the CDS had on clients, can you give me some specific examples of changes you've seen? (e.g., behavioural changes, greater success in school, fitting in better socially, financial/practical situation)
18. How do you think the CDS has contributed to those changes? In other words, are there particular aspects of the CDS that you think are most responsible for its impact?

19. Do you think the CDS is more successful with some diagnoses than others? [Probe for details]
20. Has the CDS had any impact on other agencies or sectors in your community, or on the community as a whole? [Probe for details.]
21. Is there anything you can suggest that would make it easier for you to help clients more?
22. Overall, what do you think are the biggest strengths and weaknesses of the CDS?
23. What, if anything, would you like to see changed about it?
24. That's the end of my questions. Is there anything else that you think we should know about the CDS?

[Thank everyone for their participation. Remind them that 'what's said in this group, stays in the group.']

F.3: Interview Guide for Program Administrators

Introduction

- Introduce yourselves to participant.
- Explain Consent Form and Transcript Review (e.g., “The first thing I want to do is explain to you what this project is all about and what we are asking you to do, and to get your agreement to take part.”)
- Summarize the key points of the Consent Form and have participant read through it and the Transcript Review; answer any questions.
- Have participants sign Consent Form and Transcript Review.
- Briefly give an overview of the interview(e.g., “I’ll start by finding out a bit about your background, then get some details about the program and your role in it. Next we’ll look at how you think the program impacts clients, and we’ll finish up by looking at how the program might be improved, its strengths and weaknesses. We’ll start by going around the table and getting you to introduce yourselves, but after that, you can just jump in when you have something to say—we don’t have to go in order. We do want to hear what each of you has to say, so we’ll try to make sure everyone has a chance to speak if they want to.”)

Background

“To start, I’d like to find out your background and how you came to be a program administrator.”

1. What attracted you to this job?
2. What are the best parts of the work you do? What are the hardest?
3. What kind of work or training had you done before you started in this position? What kind of training did you receive from the organization? Is there additional training that you’d like to get that would help you do your job better?

Program details

“So now I’d like to find out a bit more about your work with the [name of program]”

4. How many clients do you currently have? Has this changed over time? What do you think is the ideal number?
5. Have you taken any steps to try to increase the uptake of your program? If so, please describe. How effective do you think they have been?
6. What are the challenges to increasing the reach of your program into the target population? Any ideas for overcoming them?
7. What challenges do you face in client retention? What strategies have you tried to address these issues, and how effective have they been?

8. There is often new information that comes out on how to help people with cognitive disabilities. Can you think of any time when you changed what you do or new activities or services were added into the program, because of some new information?
9. How do you help spread awareness about FASD and your services in the community? How effective do you think these activities are?

Evaluation

“Next we’d like to find out your opinion of how effective the different parts of the program are, and how they might be improved.”

10. What models do you use for program delivery? How well do you think they are working?
11. Is the program delivered in the same manner as initially intended or planned? If not, what changes were made and why?
12. What, if any, administrative and technical challenges have you experienced?
13. How is the program progressing in terms of partnerships and collaborations with other agencies? [How often do you interact with your partner agencies? Which ones do you have the most to do with? What are the different ways in which you interact?]
14. What challenges do you face in doing your job? What kind of support do you get from your organization in meeting these challenges? How helpful is this support? How could it be better?
15. Overall, what do you think are the biggest strengths and weaknesses of this program? What, if anything, would you like to see changed about it?
16. That’s the end of my questions. Is there anything else that you think we should know about this program?

[Thank everyone for their participation. Remind them that ‘what’s said in this group, stays in the group.’]

F.4: Interview Guide for Clients

Introduction

- Ask mentor /coach to introduce you to the client.
- Explain Consent Form and Transcript Review (e.g., “The first thing I want to do is explain to you what this interview is all about and what we are asking you to do, and to get your agreement to take part”), then read them aloud with client looking at a copy.
- Ask client if s/he has any questions and answer them.
- Have participants sign Consent Form and Transcript Review documents.
- Briefly give an overview of the interview with areas of discussion, e.g., “I am going to ask you questions about what [this program] is like for you, how it has helped you, and what you think the good and bad things are about it. Remember, if there are any questions you would rather not answer, it’s okay to tell me that. Or if you are getting tired and want to take a short break, we can do that.”

Questions

Modify as needed for each program, i.e., use the program name in place of ‘the program’; use ‘coach’ or ‘mentor’ depending on the terminology used in each program; ask about specific aspects of programming offered by each organization; for FASD Support Network, tailor questions to parents.

Background

“So to start with, I’d like to find out a bit about how you first got involved with [the program].”

1. About when did you start coming to this program?
2. How did you get to know about the program?
3. What was it that made you want to come to the program?
4. Do you know of any other services or programs like this? If so, what are they? How did you get to know about them?

Program Activities

“Now I’d like to find out what you do in [this program].”

5. From what I know about the program, it has a few different parts, like [give examples of activities]. Which of these have you tried? [Make note of activities so you can refer to them in the final section of interview.]
6. Have you been introduced to any new activities through this program, things you haven’t done before? What are they?
7. Have you started using any new services because of this program? What are they?
8. How often do you meet up with your coach/mentor? What kinds of things do you do with your coach/mentor?

9. Has your coach/mentor ever helped you find other services or programs, like housing, or mental health? [If so] Tell me more about them.

Impact

“Next I’m going to ask you some questions about how [the program] has helped you.”

10. Would you say you are healthier in any ways since you started coming to [the program]? [Probes: Have you been eating better? Playing sports or going to the gym? Smoking less? Do you need to go to the doctor or hospital less often?]
11. What about your mental health—do you think your mind is working better because of the program? [Probes: Has your coach helped you make plans and follow them? Are you better at remembering things you are supposed to do? Do you think you make better choices now?]
12. How about your emotions—how you handle your feelings and get along with other people? [Probes: Do you talk to your coach about your problems? Has your coach helped you get counseling? How has that been for you? Have you met new people through the program? How has that helped you? Do you get along better with other people since you’ve been coming to the program? Have you got any help for addictions? How has that worked for you?]
13. **[For CUMFI clients only]** Would you say the program has helped you feel better in your spirit? Can you tell me about this? [If needed, explain “Spiritual health can mean different things to different people. It could be how you feel about your relationship with God or the Creator, or with nature.”](As an Aboriginal person, do you think the program is a good fit for you?)
14. What difference would you say this program has made in your life? Can you give me some examples of how things were for you before, and how they are now? [Probes: Has your housing improved? Have you gotten any work or job training? Have you learned new things that make your life better?]

Evaluation

“The last questions I’m going to ask you are about what you think of [the program] and how well it’s working for you. If there are things that you think could be better, it’s important for us to hear that. You might feel more comfortable answering these questions without your mentor/coach here, and s/he would be fine with this. Would you like him/her to leave now, so it’s just you and me? Remember that no one other than our research team is going to find out what you say in this interview.” [Mentor/coach may leave.]

“You told me about the different things you do in this program, like [give examples from interview notes].

15. Which parts of the program do you like best? What do you like about them?

16. Which parts don't you like as much? What is it you don't like? What would make you like them more?
17. Do you ever have trouble getting hold of your coach/mentor? What is that like for you?
18. Are there other ways that the program could help you, that it doesn't do now? What other kinds of help do you wish the program could give you?
19. Do you think you will keep coming to the program? Are there things that make it hard to keep coming? Can you think of anything that could be done to make it easier for you to be part of the program?
20. Now we're at the end of my questions. Is there anything else you would like to tell me about [this program]?

[Thank client for participation and reiterate how what s/he has told you will be used to help make the program better for everyone.]

F.5: Interview Guide for Cognitive Disability Strategy Clients

Introduction

- Ask mentor /coach to introduce you to the client.
- Explain Consent Form and Transcript Review (e.g., “The first thing I want to do is explain to you what this interview is all about and what we are asking you to do, and to get your agreement to take part”), then read them aloud with client looking at a copy.
- Ask client if s/he has any questions and answer them.
- Have participants sign Consent Form and Transcript Review documents.
- Briefly give an overview of the interview with areas of discussion, e.g., “I am going to ask you questions about what [this program] is like for you, how it has helped you, and what you think the good and bad things are about it. Remember, if there are any questions you would rather not answer, it’s okay to tell me that. Or if you are getting tired and want to take a short break, we can do that.”

Background

“So to start with, I’d like to find out a bit about how you first got involved with the Strategy.”

1. About when did you start using the Cognitive Disability Strategy?
2. How did you get to know about the Cognitive Disability Strategy?
3. What was it that made you want to use the Cognitive Disability Strategy?
4. Do you know of any other services or programs like this? If so, what are they? How did you get to know about them?

Program Activities

5. From what I know about the Cognitive Disability Strategy, your consultant can help with various items. What are these?
6. Have you been introduced to any new activities through the Strategy, things you haven’t done before? What are they?
7. Have you started using any new services because of the Strategy? What are they?
8. How often do you meet up with your consultant? What kinds of things do you do with your consultant?

Impact

“Next I’m going to ask you some questions about how the Strategy has helped you.”

9. What difference would you say the Strategy has made in your life? Can you give me some examples of how things were for you before, and how they are now?
10. Does the funding that you receive meet your needs?

Evaluation

“Next we’d like to find out your opinion of how effective the different parts of the program are, and how they might be improved.”

[Probes for question 11-12: wait time before getting a consultant, intake process, application/renewal process]

11. Which parts of the Strategy do you like best? What do you like about them?
12. Which parts don’t you like as much? What is it you don’t like? What would make you like them more?
13. Do you ever have trouble getting hold of your consultant? What is that like for you?
14. Are there other ways that the Strategy could help you, that it doesn’t do now? What other kinds of help do you wish the Strategy could give you?
15. Do you think you will keep using the Strategy? Are there things that make it hard for you to keep using it? Can you think of anything that could be done to make it easier for you to be part of the Strategy?
16. Now we’re at the end of my questions. Is there anything else you would like to tell me about the Strategy?

F.6: Interview Guide for Partner Agencies/Service Providers

Introduction

- Introduce yourself.
- Explain Consent Form and Transcript Review (e.g., “The first thing I want to do is explain to you what this project is all about and what we are asking you to do, and to get your agreement to take part.”)
- Summarize the key points of the Consent Form and have participants read through it and the Transcript Review; answer any questions.
- Have participants sign Consent Form and Transcript Review.
- Briefly give an overview of the interview (e.g., “I’ll start by finding out a bit about your agency and how you interact with [program], and then I’d like to know your opinion of the program and how it might be improved.”)

Tailor questions to each agency, e.g., by referring to the specific program(s) it interacts with.

Background

1. Could you tell me a little about your role in [your agency]? How long have you been with [this agency]?
2. How long has your agency been associated with [this program]?

Interaction with [insert name of program]

3. How often do you refer clients to [this program]? Do you refer clients to any other programs? If so, how do you decide where to refer clients?
4. Are there other ways in which you interact with [the organization], other than referring clients? Can you tell me about how this works?
5. Do you have any concerns about your relationship with [the organization], e.g., regarding communication, coordination of services, etc.?
6. What efforts are being made in working with [the organization] to make services more accessible to persons with FASD/cognitive disabilities? What is the capacity of your program to make these types of adjustments?
7. Have you taken part in any educational or training sessions offered by this program? [If so] How helpful would you say they were? How could they have been better?

Evaluation

“Now I’d like to get your thoughts on how well this program is working, and whether it’s making a difference in the lives of its clients.”

8. What is your opinion of the services provided by [this program]?
9. What kind of feedback have you received from clients about [this program]?
10. Do you have any sense of the impact [the program] is having on the client population?

11. Are you aware of people with FASD who are not involved in [this program]? What are the barriers to them getting involved? Do you have any thoughts on how this might be improved?
12. Do you have any suggestions for improvement in terms of services for people with FASD/cognitive disabilities, related specifically to [this program]? In general?
13. That's the end of my questions. Is there anything else you think I should know about [this program]?