Government
of
Saskatchewan

Ministry of Health
Community Care Branch
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ASD/FASD Evaluation Summary

During 2013-14 the Ministry of Health contracted three evaluation consultants to undertake a comprehensive evaluation of Autism Spectrum Disorder (ASD) and Fetal Alcohol Spectrum Disorder (FASD) programming in the province. Namely:

- Universal FASD prevention,
- Targeted FASD prevention,
- Community supports for individuals with FASD and cognitive disabilities,
- Provincial ASD services, and
- Services for adults with ASD.

The following information is a summary report of the detailed evaluation reports submitted to the Ministry of Health. It is important to note that some of the programs were only in their second year of implementation when the evaluation took place so limited outcome data is available.

Universal FASD Prevention

The Saskatchewan Prevention Institute delivers the FASD Prevention Program with the aim of working through primary prevention and using various methods to reach diverse Saskatchewan communities. The objectives of the program are:

- Provide education and promote awareness about FASD and related topics.
- Develop, collect and share evidence-based information and resources with service providers and communities.
- Support communities through outreach and the development of FASD prevention initiatives.
- Facilitate provincial communication, networking and sharing of information and resources about FASD.

Ten client/services providers were surveyed about which programs, resources and/or funding that they accessed, and the effectiveness, accessibility and impact of those programs, resources and/or funding. Respondents were asked to indicate the overall impact that the FASD Prevention Program had on increasing their awareness and prevention of FASD, and for their suggestions for improvement.

Respondents represented a variety of human service providers; Health Region Community Services, Regional Intersectoral Coordinator, KidsFirst, Addictions Services, Early Childhood Intervention Program, Family Health, University of Saskatchewan, and FASD Support Network of Saskatchewan.

Respondents indicated that the following programs were the most effective in regards to providing education and promoting awareness of FASD:

- FASD conferences 100%

Conferences make a world of differences as there is good info and good presentations focusing on FASD .

- Motivational Interviewing Training 100%

Excellent training that supports our strengths based approach. Need ongoing support. Awesome presentation by SPI very informative and a different approach to being effective in the helping field.

- FASD Day Awareness Activities 80%

Very good as it enables more community awareness and the mayor will make it official and is looked upon as quite serious Youth, students and parents are quite involved.

- FASD Coordinating Committee 80%

I e-mail or phone to stay connected and ask for assistance with projects etc. Resources are excellent, but I prefer to have speakers-more in depth material.

- Youth Action for Prevention 100%

This was huge and supportive to our region and got the youth involved to participate in a variety of learning methods. Thank you for all your work and all others from the SK Prev Institute your presence in our communities has made an impact with not only the youth but their families and adult allies.

The availability of FASD prevention resources is having an impact on regional health promotion activities according to the following comments:

We are starting to do more activities that address FASD.

Significantly with the fabulous resources that are available…it makes it easy for our committee to pull information together.

I access the promotional materials on a consistent basis. We have used resources such as the written material, speakers such as M. Himmelreich, as well as the photovoice project to raise awareness in our communities.

Other program areas had lower levels of satisfaction, but also positive comments:

- FASD Presentations, Training Sessions, Workshops 62%

Information, speakers and resources have consistently been excellent.

- FASD Speakers Bureau Member 42%

FASD speakers bureau trained one of the community workers in our region and we are better able to access information from her directly and workshops regionally.

- FASD Prevention Social Marketing Messages 66%

An effective way to get the message out en masse.

- Regional Committees 66%

We have a small Regional Committee of 6 members.

Suggestions for expanding the reach of FASD prevention programming include:

- First Nation communities,
- Junior high and high schools,
- CNYC, White Buffalo, Egadz, etc.,
- Women planning to become pregnant,
- Individuals with addictions,
- Increase elders’ engagement and involvement in workshops, and
- Daycare workers on reserves.

Some respondents noted the lack of a guiding provincial strategy for FASD prevention and the high rate of alcohol use in Saskatchewan.
An overall strategy with a wide scale approach is missing.

Saskatchewan has the highest rate of alcohol use in the country. It has become the norm. We need government officials to address this on a wide scale approach.

Targeted FASD Prevention Programs

In 2012, the Ministry of Health provided significant enhancements for intensive FASD prevention programs; these programs were to be developed in collaboration with existing community-based organizations to help ensure development of an effective program. Three health regions were invited to submit proposals for wholistic, intensive FASD prevention programming aimed at high-risk pregnant women. The projects were to bring together a range of services including: active outreach, prenatal and postnatal care, social support, addictions and mental health services, early childhood development, and paediatric rehabilitative therapies in a central location that was easily accessible to the target population.

The Ministry subsequently provided $1.2 million for three model targeted FASD prevention projects in Saskatoon, Regina and Prince Albert. The projects all provide intensive FASD prevention programming to at-risk pregnant women until their children reach two years of age. The three sites all engaged other agencies and service delivery partners to plan and/or help deliver the program so that all three programs are a combination of new programming and enhancement of existing services.

The program currently serves about 126 women, of whom a strong majority are of First Nations descent.

A total of 67 people took part in the evaluation of the three programs, including: program participants, program staff/managers, and community partners.

Participant Outcomes

Program participants were asked "What has been the most significant change for you or your family?"

The two strongest themes to emerge were:

- **Reducing or stopping use of alcohol or drugs**
- **Getting my child(ren) back**

For most participants, these two outcomes were intertwined: as a result of the program's support in assisting participants to reduce their substance use, and, in some situations, in supporting them in their interactions with child welfare workers, participants' child(ren) were returned to their care. In participants' words:

> *I didn't want to be a crackhead with nothing to eat. Now I am drug-free have a place to live and have my children back.*
>
> *They helped me keep my baby. I believe Social Services would have taken my baby like they did my previous three children. The [program] worker advocated for me and I now can advocate for myself. I really want to do what it takes to keep my baby.*

Output data from all of the program sites echoed these findings and revealed that a number of participants from each program had:

- reduced their substance use;
- given birth to infants with no alcohol use exposure; and
- had their children return to their care.

Additional themes relating to participants' "most significant change" included:

- Feeling supported - receiving practical and emotional support from staff and peers
- Improving my housing
- Felling more responsible and in charge of my life; having greater self-confidence
- Co-creating a plan for the care of my child; having more time with my children
- Learning new information
- Participating in a program on regular, ongoing basis
- Having access to transportation

Nearly all participants' comments indicated that positive changes had occurred in multiple areas of their life, and that change in one area had ripple effects in other areas. For example, one participant contrasted her life prior to the program with her current positive situation, resulting in greater self-esteem:

> *Last year I was homeless, no income, no supports, no family. Now I have my daughter, a place to live, my self-esteem.*

Similarly, a number of participants commented on the benefits of having practical and emotional support from staff and peers, and of developing friendships with people in similar situations. The support received reduced their social isolation, helped to build trust and enabled participants to feel in charge of their life.

> *I've changed so much since I got here. I stopped drinking, feel more responsible. I am making it to my appointments; I am making appointments and waking up on time. I'm communicating with staff, opening up more. I feel comfortable talking to women here.*

> *The hospital social worker sent me to employment programs, which I went to, and now I am submitting resumes for jobs.*

Another important change for several participants was that they were more involved in co- creating the plan for their child(ren)'s care and/or the amount of time they could visit with their children had increased.

> *The social worker tries to make me feel comfortable, and now that I know what the plan is for my baby I feel a lot better.*

> *I see my children more and more.*

Nearly all participants stated that it was the program staff's support that enabled them to make the significant change in their life. Staff made a difference either by providing guidance to make a needed life change (e.g., exiting an abusive relationship) and/or by being a support person/advocate in situations relating to child protection issues.

> *I got out of the abusive relationship. Talking with [program staff] three days a week and in the two groups helps.*

> *I think my kids would have been removed if the worker wasn't here. That's huge. The worker was good. The social workers would have thought that I was a bad parent. I get anxious when talking to social workers. The [program staff] will do role-playing with me to prepare for meetings with the social workers.*

Connecting these findings with those relating to participants' experience of the program, participants noted again that having a trusting relationship with staff was key to the positive changes that took place within their lives.

As well, participants' comments in relation to these "most significant change" questions reinforced the inter-connections between women's wellness outcomes (including their reduced substance use) and mothering-related outcomes (e.g., retaining or regaining care/custody and having greater involvement in the creation of the safety plan). As this participant stated:

> *Keeping my baby is top of the list. I have a belief in my ability to keep my baby and to parent. Social Services didn't open a file on me. It was a beautiful feeling.*

Lastly, in an effort to get at participants' sense of hopefulness, and using a linear scale (i.e., marking an X on a line that ran from 0% hopeful to 100% hopeful), participants were asked on the Questionnaire to indicate: "How hopeful are you that you can successfully make the life changes needed, to recover from problems with alcohol and drug use?"

In keeping with their comments about the program in general and about what they believed they are gaining from it, their responses showed a strong degree of confidence that they would be able to sustain the path they were on:

- 71%: 100% chance "I think I definitely will make the needed changes"
- 18%: 75% chance "of making the needed changes"
- 6%: 60% chance "of making the needed changes"
- 6%: 50% chance "of making the needed changes"

Program staff, managers and partners were also asked what difference they believed the program was making for participants. Overall, their responses mirrored those of the participants themselves; at the same time, program staff identified several additional outcomes. Participant outcomes, from the perspective of staff and partners, included:

- Women are engaged; they are choosing to stay connected to the program
- Women have improved relationships and trust, both with their peers and with staff
- Women have gone back to school for upgrading or higher education
- Women seem less stressed, "lighter"
- Women have improved self-confidence; they make eye contact
- Women are getting employment
- Women are 'giving back'/volunteering and better integrated in the community
- Women are relapsing less, and/or when women do relapse, they are getting back on track relatively quickly
- Women's children are developing social skills and connections with other children
- Women are becoming comfortable with child care, which makes space for their self-development
- There are fewer pre-term babies and fewer birth complications

In informants' words:

> *Women's engagement is seminal to bigger changes in their lives. Yet these changes take time. We need to be patient and loving. The fact that women are coming and continue to come is important. Previously, many women had been invisible and underground.* (Program partner)
>
> *With the support of the program, the women are getting jobs, getting their education; they're integrating in the community, volunteering. That has given then so much confidence. And it gives them a sense of purpose, when they help and volunteer. They know they're needed.* (Program manager)

Community Supports for Individuals with FASD and Cognitive Disabilities

Several initiatives support individuals with cognitive disabilities in the province of Saskatchewan including:

- 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;
- 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.

Semi-structured interviews and focus groups were completed 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 serves upwards of 750 clients, Aboriginal Family Services Mentorship Program has a usual case load of 45 clients, CUMFI Mentorship Program has 84 clients, FASD Network Family Support Program has 26 client families, and Regina Community Clinic Life Skills and Addictions Program has 93 clients.

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.

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."*

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;

> 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 FASD Family Support Program comments: *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.

- clients staying in school,

An FASD Family Support Program staff member shared a success story: *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.*

- finding and keeping 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 held down a job for almost two years.*

- obtaining appropriate housing and living independently;

A service provider commented on the inadequacy of appropriate housing for people with disabilities like FASD as a major problem: *Maintaining housing is incredibly difficult.*

A 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.*

- reduced strain on families;

Concerning a client who experiences severe anxiety when out shopping: A*fter we go to the Leisure Centre he's calm and he's back to his frame of mind.*

- clients who had been involved in the justice system completing probation orders and not re-offending;

A 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.*

- improved access to health care and medications, resulting in better treatment of mental and physical illnesses; and

The mother of a boy with autism explained that the speech therapy that CDS funding enabled her to pay for has helped her son: *He went from being completely non-verbal to actually having like a vocal vocabulary of around 80 words.*

A staff member noted: *Providing ongoing assistance prevents people from accessing the most expensive systems such as emergency rooms. . . 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.*

- clients managing their addictions.

Addictions counselling at CUMFI 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.*

- 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.

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.*

Parents commented that their FASD Family 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.*

An RCC 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.*

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.

Evaluation participants described several ways in which program 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
- enabling existing programs to expand their offerings and hours.

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)
- 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.

Regional ASD Services

The *Framework and Action Plan for Autism Spectrum Disorders Services in Saskatchewan (Framework and Action Plan)* was implemented in 2009 to address some of the gaps in the continuum of care by aligning and enhancing existing services and support. Since that time services have been enhanced and currently include a continuum of services and supports including ASD Consultants, ASD Support Workers, rehabilitative therapies, respite services, and training for service providers and parents. The aim is to better meet the needs of the target population and when appropriate, integrate all services provided to an individual through the Autism Spectrum Disorders (ASD) Consultant.

Regional ASD Services currently serve 1,408 children aged 0 – 18 years old. Twelve clients/families and thirteen service providers were interviewed and a focus group was held with the regional ASD Consultants. Common themes that emerged from the ASD evaluation include:

- **Parents are generally satisfied with the quality of services from the ASD Consultants and Support Workers; and,**
- **Parents are not satisfied with the number of service hours offered to their children.**

Specific parent responses include:

- 78% of parents are very satisfied with the services provided by the ASD Consultant; however, only 25% of parents are very satisfied with the frequency of services provided.

Our consultant/clinician is excellent, however it is clear that she does not have the time given her caseload (common for all clinicians) and the mandate of RQHR that preschool age children are the focus for time and resources.

Generally dissatisfied with availability of services - attention of consultant is excellent and would be rated "5" - frequency of services and supports is deficient due to availability of services.

- 90% of parents are satisfied with the services provided by the ASD Support Worker; however, only 33% are satisfied with the frequency of services provided.

Parents report that their preschool children are commonly accessing one or two hours of service per week.

This Support worker is knowledgeable, has been trained in ABA Behaviour Approach and is extremely talented. She has the ability to encourage children to work on different task and is also mature enough to be able to deal with parents which is a feat onto it's own.

Services provided are excellent but there is insufficient availability of services. More needs to be provided.

If the intent is to provide programming for a child then 2 hours per week is woefully inadequate.

- Similarly, 60% of service providers are satisfied with the frequency of services provided and note that it does not meet best practice standards.

Again, the support worker does not have enough time to provide the level of support recommended in the research literature for the treatment of children with autism (30hrs/wk of intensive intervention). In our region, children receive 2-4 hours of intervention per week from the support worker. An additional difficulty is that support worker position has often been vacant in our region.

- 67% of parents stated that their child had a team of service providers who met to plan and coordinate services. The team most often included speech language therapists, occupational therapists and resource teachers in addition to the ASD Consultant; however, many indicated concerns with how often this is happening and whether all the right service providers are involved.

These are the people involved with our son on paper, as far as everyone meeting as a whole group? This has not happened unless it is an extreme measure about behaviors.

It would be beneficial for my child to have an OT, PT, SLP, on his team ON A CONTINUING BASIS. It would also be nice to have a team effort to assist with summer respite, activities etc.

The Educational Assist needs to be receiving instruction from the O/T, Support Worker, ASD Consultant and Speech Pathologist so that everyone is on the same page. Right now it appears that the Education Assistance at the day care is doing most of it on her own.

Because of the Autistic Consultant in Heartland HR, she was able to assist in pulling many Ministries in order to have my son's transition needs met i.e. education, mental health, health, CLSD. If it weren't for her, I wouldn't have known how to access these people. All were crucial in my son's life. I think crossing all the Ministries should be the norm in transitioning.

- 78% of parents said they accessed respite services and 71% were satisfied with the service.

The Program is run well, however if children were receiving intervention/programming throughout the year the Summer Program would be much more effective and valuable.

Given it's trying to incorporate multiple levels of programming (communication/social skills/cognitive etc.) for multiple people in a short time it's done extremely well.

- Parents indicated that there children most commonly accessed speech language pathologists (16%) and occupational therapists (16%) in addition to the ASD Consultants and Support Workers; however, they are not satisfied with the frequency of service provision.

Monthly only, school from 9-5. In fact from my experience, OT, PT and SLP services are almost non existent within the school system and we are unable to access health region services as it is now education's responsibility. So I have been told.

The KCC (Saskatoon) only offers funded services to children less than 5. My son is 6 and is no longer eligible. The public school system apparently has an OT and SLP for the city, my child never received individualized service or adequate funded intervention because one person was stretched among too many students in multiple schools.

- Parents indicated some concerns with accessing intensive needs programming at schools and daycares.

This is difficult to answer b/c our son requires intensive services but I wouldn't say he is on one. He receives additional supports but not intensive by definition. He has a full time EA but gets very little time from the SLP/OT etc.

Receiving an enhancement grant through the Ministry of Education however in the month of Sept staff were so busy trying to transition other children into the schools that they had no time to provide any quality of services to my child or direction to the Educational Assistance in the day care. This was not the fact that the staff did not want to assist my son just the fact that there are not enough staff to deal with all the demands when school starts. No matter what the reasons were, my child was the one who fell through the cracks. I did inform both my O/T and Support of how I felt and that this was not acceptable.

- 80% of parents have purchased private therapy services for their children.

Over the past 10 years a variety of services have been purchased. For the past 3 years we have been sending our son to private therapy 4 days a week during the school year for 3 hours/day and 5 days a week for 3 hours/day in the Summer. Depending on the month the monthly fee is approximately $1700.00. We also pay two people to take him on outings though its not scheduled.

- 20% of parents report that the public system is currently meeting their children's needs.

We are still waiting for Speech, and have limited contact or services through the Autism Centre Support Worker or the O/Therapist. The only person who we are having contact with is the Education Assistant who is not trained in ABA and has been provided with little instruction.

I would say we are trying to meet his needs by removing him from school to get the therapy he requires. The issue is that we have to remove him to achieve this. From my perspective his needs are not being met b/c the educational system is not even remotely close to being prepared, trained, staffed etc. to manage children with Autism let alone teach them.

Research evidence indicates autism requires intensive therapy early intervention. No intensive early intervention exists in Saskatchewan and the government is not funding at the required level.

- Parents commonly mentioned that their children need more access to occupational therapy, speech language therapy and suitable school programming.

More frequent OT and Speech and social community programs throughout the year.

In order for a child to learn in the school environment a program must be in place that works on their issues related to Autism. This includes working on behavours, sensory, communication (many teachers and EAs don't even have PECS training), cognitive therapy, etc. You cannot teach a child to write, or the alphabet or do math if you cannot understand how they learn these things. The programming has to incorporate personal individualized therapy for Autism that also ties into teaching school curriculum. The only way this happens is by removing the barriers and allowing collaboration between all systems and private service providers (in this case Health and Education). As well worrying about who is funding it is ridiculous. I know each system has a budget to meet but maybe a "pooled" budget needs to be created for this type of programming, this would assist in removing some of the barriers of who is responsible for what and focusing on providing what is needed for the child.

Services for Adults with ASD

Services for adults with ASD are primarily provided by the Autism Resource Centre in Regina. ARC provides vocational assessment and skill building, and life skills development services to about 30 individuals. The Ministry of Health is also supporting a pilot supportive living project, which currently serves two individuals. Five clients and five service providers were interviewed and a focus group was held with ARC staff. Major themes that emerged from the evaluation results are:

- **Satisfaction with services received from ARC;**
- **Difficulties with unemployment/ under employment; and,**
- **The need for supportive living services to support increased independence.**

Specific client/parent responses included:

- 100% rate ARC programs as good or very good; however, there is some concern about waiting for services.

The PAES program was very good and very helpful, however when our son's session was over he had to go to the bottom of the list again and now wait until his turn comes around again to continue into the next phase of what he was learning and to see where he would best fit in for more work opportunity. This puts adults with Aspersers often back to the beginning as the consistency is not there, so sometimes hard for them to continue where they left off months or even a year later.

- Parents/adults identified the need for more services related to finding employment and long term job coaching.

Help in finding employment and job coaching, frequency in attending the PAES program to be able to find out what type of job is best suited for our son, then help in finding a job in that area and job coaching until settled in and working to standards.

Help in finding a suitable job and then support in it.

- Adults commonly need support to complete many activities of daily living, and identify this as one issue that prevents them from living more independently.

I am able to do the tasks listed above, but am not totally self sufficient in all areas. I would need more experience with general household tasks and responsibilities such as laundry, ironing and such, to expand on the skills that I already have.

Living with support and working on the items listed above as well as daily living skills in housekeeping and maintenance.

Life Skills programs that I need to help my transition to living independently. We used to get support from a Family Support Worker that began the teaching process with cooking and grocery shopping, but it is not supported anymore through ARC on the individual basis.

The Cooking program is a great idea, along with the life skills and apartment housed within ARC. We believe there is a need for more life skills training and potentially some one on one - for example - grocery shopping and other activities that are hard to replicate in the classroom setting.

- 80% of adults are employed (4 – 14 hrs/week), but they commonly feel under employed as 67% report that they would like to work more hours.

- Clients who accessed ARC employment assistance were satisfied with their experience, while those who accessed Partners in Employment (PIE) were not satisfied.

ARC has done everything they can to help secure employment.
ARC has been instrumental in helping to secure employment and by providing the job coaching. The coaching is in transition for Partners In Employment (PIE) to take ownership of my job file but PIE has not been a good experience thus far. We have had numerous individuals that we have been in contact with at PIE, but they are always moving on or being replaced. There has not been any consistency, so we are even more thankful for ARC and the support they have provided.

We have tried PIE to help find a job, they were often temporary and the job coach had too many people to support so wasn't able to give the time needed to help him be successful. The last time we were on their list months went by, they were not able to find a job. Our son was expected to search out jobs on his own, this is what he is not capable and skilled at doing, one of the reasons we sought out help. He was told if he didn't do job searching on his own, they couldn't help. He had to be more motivated. The idea for us was that with someone helping him, he would be more motivated. We learned that this is not how it works there and they couldn't help without him being more independent.

- Employers report being very satisfied with ARC services, while having some concerns with consistency of PIE services.

The ARC Consultants were very flexible - we are contacted every 3 months and 6 months.

ARC Consultant met with our employee at the workplace first, and consulted with the employee for the first 6 months, then PIE provided the check-in.

There is ongoing coaching support, however this has been inconsistent from PIE and yearly contact.

We are very satisfied with ARC, they were available to answer any and all questions, no questions were considered stupid.

I refer to the ARC as the "Awesome Resource Centre" - they have really made a difference with the people we work with.

- Employers offered some advice from their experience with providing jobs to ARC clients.

Need a clear process guide for employers who want to be involved i.e. brochure, Website.

Our employee spoke up in front of other employees in the workplace and charmed us all!

We had a lunch and learn that had an overview of Autism - there was great participation - our employee was featured with a site announcement and picture - our workplace is very social and he is part of the team.

Change the labels we put on people, we don't realize their potential.

Summary

Overall, the evaluation results reveal that ASD/FASD programming is well received by Saskatchewan's population. Generally, respondents are satisfied with the quality of current programming; however, they identified the need for the spread of existing programs in certain regions to the whole province, and the need for additional or more intensive services throughout the province. In addition, respondents noted several opportunities to improve the operation of the Cognitive Disabilities Strategy.