DIAGNOSING FASD IN ADULTS: THE DEVELOPMENT AND OPERATION OF AN ADULT FASD CLINIC IN ONTARIO, CANADA

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ABSTRACT

This paper describes the development and operation of an interdisciplinary Fetal Alcohol Spectrum Disorders (FASD) diagnostic clinic focussing specifically on adults. The clinic is embedded within a community-based interdisciplinary health agency specializing in intellectual and developmental disabilities. A review of the clinic's assessment process is presented describing the steps from intake to feedback and intervention. To date, the clinic has received 93 referrals and given 41 alcohol-related diagnoses including 10 completed using videoconferencing technology. Issues unique to adult diagnosis are discussed as well as some of the challenges, including high rates of cancellations/no-shows for appointments, obtaining background and historical information, establishing maternal alcohol history, working collaboratively with other support sectors such as children's protective services and the justice system, and finding appropriate follow-up and intervention services in the community. Recommendations for future work to support adults with FASD and their families are presented.

Key Words: *Fetal alcohol spectrum disorder, FASD assessment, adult, diagnosis*

An important initial step in supporting adults with Fetal Alcohol Spectrum Disorders (FASD) is identifying individuals affected through accurate diagnosis. Although diagnosis in childhood is preferable for many disorders including FASD[1], diagnosis at any point in an individual's life can lead to greater understanding, more availability of services, and more effective interventions. This paper outlines the development and operations of the Surrey Place Centre FASD Adult Diagnostic Clinic, a resource created specifically to assist individuals over the age of 18 in need of FASD services. The goal of the paper is to provide information to service providers who may be developing or planning to develop their own adult FASD resources.

FASD describes the type of deficits which can occur in an individual exposed to alcohol prior to birth.[2,3] It is a life-long disorder with disabilities and challenges that begin in childhood but persist into adult life.[4,5,6,7] Adults with FASD frequently require significant supports in multiple aspects of daily living and unlike children they may not have schools, families, or other sources of structure to help them manage. Those who do not receive their FASD diagnosis until adulthood and consequently do not receive proper supports during childhood may face even greater disadvantages. This can lead to complex secondary problems such as homelessness, mental health issues, substance use, unplanned parenthood, or justice system involvement.[1,8]

Why do we need FASD diagnostic services specifically for adults?

Currently in many regions of Canada, and perhaps internationally as well, there is no clear path to obtaining a diagnosis of FASD in adulthood.[9] Individuals who do not receive diagnosis as a child often have to search broadly for supports across many different service sectors before finding expertise in this area. One reason for this difficultly is that FASD is generally viewed as a childhood disorder and therefore often linked to children's services. In some cases, clinics providing diagnosis will exclude adults due to a lack of professional expertise to work with this population (e.g., clinics staffed by paediatricians or child psychologists).

At present, Canadian diagnostic criteria for FASD [2] in both adults and children are the same but a number of differences between assessing children and adults have been noted. It has been suggested, for example, that the facial features and growth retardation sometimes seen in children with FASD may normalize as they as reach adulthood.[5,10] This could make identification potentially more difficult with age. It is also likely that individuals with severe alcohol exposure and more significant intellectual deficits will be identified and diagnosed as children, leaving more subtle deficits and presentations undiagnosed until adulthood.

When working with adults with FASD, both during and after the assessment, a variety of different adult support sectors and services will need to be engaged. In many cases, adults are referred for assessment by the justice, mental health, or social services systems and it is important for diagnostic team members, particularly clinic coordinators, to understand how to navigate these and other adult-based systems.[11] Follow-up and referral to appropriate agencies, help in applying for residential and financial assistance, connecting individuals with primary healthcare providers, and consideration of other adult specific challenges (e.g., child custody, substance use, financial management) are all unique and important to adult diagnosis in FASD.

Making adult FASD diagnosis more broadly available would also be a significant step towards prevention efforts aimed at future generations who may be at risk of prenatal alcohol exposure. In their Alberta clinic, McFarlane observed that about 40% of adults diagnosed with FASD had become parents themselves.[12] Add to this the findings from other studies[13,14] reporting very high rates of alcohol use and abuse in adults with FASD and the potential risk for these individuals to give birth to children who are also exposed becomes apparent. More specific evidence of risk comes from Streissguth et al. who found that in a sample of 30 females with FASD who had parented a child, 40% were drinking during their pregnancy.[14] These studies highlight the importance of adult clinical services for FASD.

Adult FASD Diagnostic Clinic Description

The Adult FASD Diagnostic clinic at Surrey Place provides assessment, diagnosis, short-term treatment, referrals and recommendations to individuals 18 years of age and older. The team is embedded within Surrey Place Centre which is a provincially-funded community health agency serving individuals with intellectual and developmental disorders of all ages. It is located in Toronto, Ontario the largest city in Canada and has a catchment within this city. The Centre is an out-patient service which provides a variety of clinical supports including primary medical/nursing care, psychiatry, psychology, speech-language pathology, social work/counselling, service coordination, occupational therapy, behaviour therapy, and audiology.

The FASD adult diagnostic team is composed of the following professionals: clinic coordinator, nurse practitioner, consulting physician, clinical psychologist, speech-language pathologist, and behaviour therapist. Other professional services such as audiology, occupational therapy, psychiatric assessment, and counselling are available within the larger host agency for individuals who meet criteria for the agency's services. Referrals are accepted for all individuals who present with functional deficits in daily life. A previous diagnosis of intellectual disability is not required for referral to the Adult FASD clinic, however it may be required for follow-up support and intervention services from other departments within Surrey Place Centre and the broader developmental sector.

History and Development of the Diagnostic Clinic

Development of the adult diagnostic clinic began in 2006 after several front-line clinicians working within adult services at Surrey Place

Centre noted a large number of complex and difficult to serve individuals who appeared to have prenatal alcohol exposure in their history.

These individuals presented with a different constellation of difficulties and challenges when compared to other adults with developmental disabilities including more problems with homelessness, frequent substance use, early pregnancies, and legal system involvement. Clinicians observed that these individuals were not well understood or supported and sought a new theoretical framework to understand their needs. At that point in time there were very few diagnostic resources available for adults in Ontario with alcohol-related disabilities and those that did exist were paediatric clinics which had broadened their scope to assist adults as well as children.

The first step in the development of the clinic was the formation by agency staff of a special interest group aimed at improving clinician education and understanding of FASD. Clinicians in the group attended professional development workshops and conferences on FASD over a period of several years to become familiar with the disorder and issues surrounding it. As well, clinicians completed the University of Washington on-line course in diagnosis.[15] Following this, clinicians partnered with an established FASD diagnostic clinic to work together on several cases.

After completing this education and training, the special interest group submitted a formal proposal to Centre management to create a clinic devoted specifically to adults with FASD. The proposal requested protected time for clinicians to meet monthly as a group and perform 12 assessments per year, or approximately one per month. The proposal was accepted as a pilot project in 2007 and designated as an ongoing program one year later having demonstrated the utility of the service.

Overview of the FASD Adult Clinic Process

Referral

The first step in the diagnostic process is receiving referrals from the community. The clinic accepts referrals from any source including self-referral, family, or other professionals. The clinic coordinator plays a key role in receiving referrals, speaking to individuals referred by phone to explain what the FASD assessment entails and gaining consent to contact others who may be able to assist in the process. Consent forms are sent out by mail, often to the referral source, who is then charged with having them signed and returned. In addition, the coordinator will attempt to identify a key support person, either a professional or family member, who will accompany the individual to clinic appointments. Due to frequent difficulties with executive functioning skills such as organization and time management[16], individuals referred are often unable to complete the entire assessment process without support. The support person is generally charged with helping the individual with attending appointments, following up on other referrals for service, and managing information.

Before a referral is presented to the full team, the clinic coordinator must either have an individual identified who can report on maternal drinking or have documentation which states the biological mother consumed alcohol in the pregnancy. In cases where it is possible to contact the biological mother or father, permission from the individual referred will be obtained before any contact is initiated. A frank discussion of the risks and benefits of pursuing an FASD diagnosis (e.g., possible damage to the relationship between child and parent) is also undertaken with the individual referred during the first clinic appointment. In cases where it is not possible to contact a biological parent, other individuals involved with the family may be approached. Frequently, this will be a grandparent, aunt, or uncle who might have lived with the biological mother during her pregnancy. Past medical or children’s services records (i.e., Children’s Aid Society) may also document maternal drinking during the pregnancy especially if the agency was involved with the biological family for an extended period of time due to older siblings at risk. In our experience, obtaining a detailed history of maternal alcohol consumption for adult referrals, such as dose and frequency throughout the pregnancy, is rare.

Information gathered is often general in nature (e.g., mother was observed to drink on weekends and appeared drunk). Collateral information regarding a biological mother's long-term alcohol issues or medical problems resulting from alcohol consumption can also strengthen the evidence available from family members and other informants.

Pre-assessment team discussion

After gathering all the documentation possible, the clinic coordinator presents the case to the full FASD team at a clinical meeting. The team decides together: a) if there is enough evidence to believe that the biological mother drank potentially harmful amounts of alcohol during pregnancy as defined in the Canadian Guidelines for Diagnosis b) the individual to be assessed has evidence of impairment in daily functioning over a period of years indicative of early alcohol exposure c) what information is missing from the picture d) what functional testing needs to be completed. In cases where an individual already has a valid and relatively recent psychological or communication assessment it may not be necessary to replicate it. In most cases, however, additional testing will be needed for areas less typically assessed by other clinicians such as social communication skills, memory, executive functioning, and adaptive daily living skills. In cases where there is a family history of mental health or developmental disability, physical dysmorphology, or other indicators of a possible heritable disorder, referral for genetic assessment will be made.

Clinicians have protected time allotted every month for FASD assessments. If the team agrees to go forward, the individual and their referral source/support are contacted and booked by the coordinator for the next available allotted appointment. All documentation on the individual is copied and given to each tea member involved in the assessment to read prior to the assessment day.

Intake and assessment

All team members involved in the assessment attend the intake meeting with the individual and their referral source/support. This is desirable as it limits the number of times the individual must tell their story to different professionals. Questions about the current situation, reasons for the referral, the individual's immediate and longer term needs/goals, medical/social history, family medical/social history, and the individual's understanding of the implications of receiving a diagnosis are addressed at the intake meeting. This lasts approximately one to one and a half hours.

Following the intake meeting, the individual begins the direct assessment component of the day with a hearing (audiological) test completed in a separate room. While he or she is being tested, the referral source/support is questioned about maternal alcohol history (if appropriate), daily living skills, and any other issues that might be sensitive and require privacy. Following the audiological assessment, the individual sees the nurse practitioner privately for a medical examination, neurological screening, facial measurements, facial photographs, and to discuss more private medical issues (e.g., substance use, sexual activity etc.). After this, the psychological and communication assessment are performed, usually with each professional taking turns testing and observing behind a two way mirror. The most informative tests and those judged most likely to yield information about deficits are performed first allowing both professionals to have at least some information after the first encounter in case follow-up appointments cannot be arranged. Table 1 gives an overview of a typical neurodevelopmental assessment battery including tests performed by the nurse practitioner, speech-language pathologist, and the psychologist.

TABLE 1 Typical Neurodevelopmental Assessment Battery for Adults with suspected FASD

Domain of Functioning	Tests / Measures Used
Motor / Sensory motor	Neurological Screening* Beery-Buktenica Developmental Test of Visual-Motor Integration-6[26]
Brain Structure	Head circumference measure*
Cognition	Wechsler Adult Intelligence Scale-IV[27]
Communication	Clinical Evaluation of Language Fundamentals-5[28] Test of Auditory Processing Skills-3[29] Peabody Picture Vocabulary Scale-4[30] Expressive Vocabulary Test-2[31]
Academics	Wide Range Achievement Test-4[32]
Memory	Wechsler Memory Scale-Abbreviated[33]
Executive Functioning	Behavioural Assessment of Dys-executive Functioning[34] Behavioral Rating Inventory of Executive Functioning-Caregiver report[35]
Daily Living Skills	Adaptive Behavior Assessment System- 2[36] Assessment of Language Related Functional Activities[37]

*Tests completed by the nurse practitioner. All others listed are completed by the psychologist or speech-language pathologist.

The intake/assessment day lasts approximately 4 hours in total if the individual is able to tolerate it, with frequent breaks, coffee, and changes in activities and rooms. Generally, the entire battery of tests cannot be completed in this time period and a second and possibly third appointment is made to complete the direct assessment component.

Team formulation discussion

At the next meeting of the diagnostic team, results of the previous month's assessment are discussed. The team uses the Canadian Guidelines for Diagnosis of FASD.[2] All team members have input into the decision around diagnosis and consensus is reached through discussion and review of assessment findings. Recommendations are offered by each discipline as appropriate.

The psychologist and speech-pathologist each create brief reports of their findings and pass these on to the nurse practitioner. The final diagnostic report from the entire team is created by the nurse practitioner and includes a detailed history, medical results, sections taken from the psychology and communication reports, a final diagnosis, and the team's recommendations.

Feedback

Providing diagnosis and feedback to adults with FASD requires a great deal of preparation, empathy, and thoughtfulness. Generally, the adult is asked to come to the feedback appointment accompanied by the referral source/support person but is then invited to come privately into the treatment room first to discuss the results with the team before inviting the support person into the room. This reinforces the fact that the information about diagnosis is confidential, that he/she controls who receives it, and that it is important to consider carefully who else will be told.

Making information about the diagnosis understandable and acceptable to adults with FASD is a challenge. It is necessary to avoid technical language, discuss how the diagnosis may benefit them, and anticipate possible negative reactions such as anxiety, blame directed at parents, and self-esteem issues. To aid with understanding, several visual supports (charts and images) were created by the team to use in feedback to help explain FASD and what the diagnosis means. As well, because there is a great deal of complex information to be processed and acted on the team will typically offer two to three additional follow-up sessions to review the diagnosis in greater detail, explain and focus on the recommendations, complete paperwork for financial or job support, and offer psycho-social support to the individual or their support person. Often, the individual initially rejects or is indifferent to the FASD diagnosis and it may take several months for them to come back for these additional feedback sessions.

Intervention/follow-up

Many of the adults seen in the clinic present with a specific goal in mind. Often, it is to help them qualify for financial support or some other form of community service such as vocational support or specialized housing. The clinic coordinator frequently assists with these needs by offering short term case management and referral to community services. The clinic also receives many referrals from the legal system to help support applications for mental health court diversion or some form of mitigated sentencing. All of these concerns and issues are addressed at the intervention phase. Frequently, counselling or behaviour therapy services are offered to the individual and/or their supports to help with understanding the diagnosis, planning interventions, and environmental adaptations that may be put in place to improve daily functioning.

Clinic Diagnostic Outcomes

Since its inception in 2007 the Surrey Place FASD Adult Diagnostic clinic has accepted 93 referrals and provided 41 alcohol-related diagnoses, keeping to its mandate of approximately one diagnosis per month. Fifty of the 93 individuals referred were male. Of the 41 who received a diagnosis, 37 were classified as having Alcohol Related Neurodevelopmental Disorder (ARND), 2 as Partial Fetal Alcohol Syndrome (pFAS), and 2 as Fetal Alcohol Syndrome. Of those not diagnosed, 24 withdrew from services or could not be contacted to proceed with the assessment. Another 28 did not proceed because of an inability to confirm maternal alcohol history or the referral was found to be inappropriate or only a consultation was required (e.g., a diagnosis had already been given in childhood and consultation for current support staff was needed).

Of the 41 individuals receiving an alcohol-related diagnosis, 24 (59%) were found to be eligible for developmental services in Ontario and able to access supports in the developmental disabilities sector. Another 17 (41%) were not eligible for developmental services and did not receive follow-up from this sector. This was generally because their IQ scores and adaptive daily living skills placed them in the Average Range of intellectual ability and they were therefore judged not to fall into the population served by the developmental disabilities sector at this time. In some cases these individuals were referred on to other service providers (e.g., generic mental health) but in other cases no appropriate support could be found within the community. This lack of support and follow-up for a significant number of individuals is problematic and frequently results in individuals falling through the cracks of service sectors and experiencing poor outcomes due to a lack of support.

Also within the 41 alcohol-related diagnoses described above were 10 completed via videoconferencing. Clinical videoconferencing services have been offered by the host agency Surrey Place Centre for over 10 years. The service is offered to smaller communities in northwestern Ontario which have minimal access to specialized clinical services for adults with developmental disabilities. Adult FASD assessment was incorporated into the existing clinical videoconferencing service after requests were made by the communities. Intake, psychological testing, feedback, and follow-up interventions were all completed online, while medical assessments were completed locally by a family physician/nurse practitioner. Facial measurements were also done either by family physicians or by videoconferencing team members who travelled to the northwestern communities on twice yearly visits (please see

Temple et al.[17] for a description of videoconferencing psychological assessment procedures). Referrals for other medical services such as genetic evaluation or physical health issues were requested and made through family physicians.

Challenges in Operating an Adult FASD Clinic

Some of the most significant challenges facing an adult FASD clinic include gathering and evaluating historical and background information including maternal alcohol history, physically getting individuals to clinic appointments, and locating appropriate individuals to provide information about the adult being assessed. Gathering information about maternal alcohol history becomes especially complex when 18 years or more have passed since the index pregnancy and many complicating factors have occurred to impact the individual's functioning since that time. It is sometimes possible to interview biological mothers directly but in many cases it is necessary to rely on report from other family members or on medical/legal records. Frequently, there are conflicting stories about the quantity and character of the maternal consumption and the team must then make a determination under less than ideal circumstances. Weighing the credibility of various sources of information as well as the relevant contribution of many different biological and environmental factors can be difficult. Extended discussions on this topic often occur and these can be time consuming for the team.

Because many individuals seen at the clinic have difficulties with planning, organizing, and managing their time, cancellations and no-shows are very common. Unlike children presenting for FASD assessment who are generally accompanied by a guardian or parent, adults often come without consistent supports or caregivers. Re-scheduling cancelled assessments means that relative to other types of interdisciplinary work FASD assessments tend to take longer to complete. Because of these difficulties it may be advisable for team members to consider having back-up activities planned to ensure that the scheduled time when no-shows or cancellations occur can be used productively.

Another challenge in working with adults is obtaining reliable information about the individual's day-to-day skills, behaviour, and history. In the context of an FASD assessment reliable informant report is very important for assessing areas such as executive functioning, mental health, and adaptive daily living skills. Adults referred for FASD assessment often live away from their parents or caregivers and may have no one familiar enough with them to give an account of their past and present activities and behaviour. As well, the individual may not remember or be able to report reliably or insightfully on their own challenges making informant report critical for understanding the full picture.

Advantages and Disadvantages of the Embedded Team Model

In considering the different types of models for creating an adult FASD team (e.g., free standing clinic, virtual team, hospital-based, embedded), there are several advantages to the embedded model when it is placed within a developmental/intellectual disabilities sector agency. First, all of the clinicians necessary for an FASD diagnostic team are generally part of such an agency already. Because of this they may also be familiar and comfortable with interdisciplinary work of this kind. Infrastructure costs will be minimal because all of the materials, office space, meeting rooms, and administrative supports will already exist within the host agency. As well, given that individuals with FASD frequently require a high level of structure and supervision, their support needs are often quite consistent with the types of supports offered within the developmental sector where it is understood that people will require life-long assistance. Performing the FASD assessment and diagnosis within the developmental sector may then help with providing more seamless service since individuals can be referred on to further supports within the same sector or agency.

Embedding FASD diagnostic services within the developmental sector also carries some disadvantages. Although a diagnosis of FASD presupposes significant deficits, in about 50% of cases these deficits exist within the context of Average (or greater) intellectual ability. Having a higher level of intelligence, some adults with FASD don't wish to be identified with other individuals with an intellectual or developmental disability. This makes it difficult to include them successfully in existing services and group settings such as supported residences, day programs and group interventions. As well, some service providers in the developmental sector may see individuals with FASD and Average intelligence as not fitting their mandate and may be reluctant to include them in programs. When this occurs, finding interventions and follow-up services can be very challenging since adults with FASD also do not always fit neatly into any other existing sector.

Of the 41 adults diagnosed with FASD at the Surrey Place Centre embedded clinic, 17 (41%) did not qualify for follow-up developmental services because their IQ and/or adaptive daily living skills scores were within the Average Range. This highlights an additional challenge for adults with Average to high Average intelligence. To be considered for developmental services individuals are required to present with evidence of long-term difficulties with daily living skills such as problems during school, difficulties gaining employment, or challenges maintaining a residence. If such a history is not reported, as is sometimes the case for high functioning individuals, it is possible to be screened out at the referral stage and thus not have access to FASD assessment services within an embedded developmental clinic. In Ontario, adult developmental services can now include individuals with significant deficits (standard score below 70) on *two of four indices* on a standardized IQ test rather than only individuals with an overall (Fullscale) IQ score below 70. In practice this has meant that some adults with scores in the Borderline to Low Average range of intellectual ability are now eligible for developmental services if they also present with significant deficits in daily living skills. These changes were made in recognition of the fact that many adults with disabilities such as FASD and Autism Spectrum disorder are functionally similar to individuals with much lower IQs and would benefit from developmental services. Despite these changes however, not all individuals with FASD will be captured in this group and some higher functioning adults will not be eligible for services.

Future Issues and Considerations for Adult FASD Services

As adult diagnosis of FASD is a relatively new field there remain several important areas to be addressed by social services agencies and researchers in order to improve diagnostic outcomes and follow-up services. These include better strategies for transitioning from children's to adult support services; more specialized supports for commonly encountered difficulties including financial management, vocational activities, and residential options; and more emphasis on developing and evaluating intervention strategies for adults.

One service that is critical in promoting positive outcomes for adults with FASD is having consistent service providers or agencies that can remain available to help solve problems as they arise and connect the individual to community services and structured programs.[4,18,11] A frequent difficulty is that adults with FASD do not qualify for long-term case management or support workers because they do not have a developmental/intellectual disability or a significant mental health disorder. Making such supports available to all adults with FASD would be an important step towards providing the structure and stability necessary to reduce adverse outcomes.[11]

Moving into adulthood, individuals with FASD become legally entitled to manage their own affairs including finances, vocational decisions, and residential placement. Unfortunately, it is sometimes the case that they will make impulsive decisions which are not ultimately in their own best interest. Service providers and family members may then have to stand by and watch the consequences of these decisions unfold which can be very stressful and upsetting. In this regard it may be helpful to have plans in place prior to transitioning into adulthood which allow for structure and support to be there when the individual becomes an adult.This could include joint guardianship of finances, structured job placement programs, and pre-arranged supported housing. Many individuals/families have found it helpful to have arrangements such as joint banking accounts where money is carefully controlled and dispersed in small amounts each week. Others have noted that residential placements where routine support, prompts, and supervision are in place are the most likely to be successful. All of these interventions will require that caregivers or service providers are aware of the challenges of FASD going into adulthood and move to ensure that problems are avoided before they occur by managing the transitions carefully.

In the area of interventions, there are currently very few evidence-based options available for adults with FASD.[19] An area which has received some attention from researchers is community support/education programs to assist women with FASD who are at risk of having children with FASD. These programs have shown positive results and highlight the importance of having case management services to allow individuals to connect with community and healthcare supports as needed.[20,21] Interventions being implemented for children with FASD such as behavioural regulation training [22] may be effective for adults but await research to provide evidence of their utility.

Despite the challenges there is reason to be optimistic about the prospects for improved diagnostic and intervention services for adults with FASD. More diagnostic clinics are appearing across Canada[23,24] and more information than ever before is available to families, individuals, and service providers through educational workshops, conferences, and internet resources. Interest in the field is growing across many sectors (e.g., justice, developmental services)[11,25] and this may bring with it more research that will ultimately result in better supports and services for adults with FASD.

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