

Research in Diagnosis

Linking diagnosis and prevention: building the next generation of policy responses

For many of those associated with Fetal Alcohol Spectrum Disorder (FASD) diagnosis, intervention, and prevention, there remains a mysterious aspect to the condition. When FASD was first identified in the 1970's as the leading known cause of developmental delay, and the only disability of its type that might be called "100% preventable", it was thought that the link between diagnostic and prevention work would be clear, uncomplicated, and achievable.

Overview

For many of those associated with Fetal Alcohol Spectrum Disorder (FASD) diagnosis, intervention, and prevention, there remains a mysterious aspect to the condition. When FASD was first identified in the 1970's as the leading known cause of developmental delay, and the only disability of its type that might be called "100% preventable", it was thought that the link between diagnostic and prevention work would be clear, uncomplicated, and achievable: FASD, and the range of physical, cognitive, and daily living challenges linked to prenatal alcohol exposure could be prevented completely if women planning pregnancies quit drinking. Likewise, once the range of impairments and functional difficulties of people diagnosed with FASD were codified and elaborated, a road map for providing supports to individuals and families would also be achievable. Although many promising practices have been developed and implemented, efforts to achieve and sustain prevention of FASD at a population level have been, and remain, elusive (Clarren and Salmon 2010).

One reason that so much basic work still needs to be done seems to be related to a failure of FASD to be incorporated into the general cloth of medical work or easily addressed and accommodated in systems like education, social services, mental health, justice, and so on. We need to evaluate what we are doing, how it might be done better,

and then to implement and disseminate change (Salmon and Clarren 2010). The Canada Northwest FASD Research Network is committed to demystifying FASD diagnosis, intervention, and prevention through evidence-based research that promotes integrated approaches which link: compassionate and timely care for pregnant women and mothers with substance use problems;

accurate and meaningful FASD diagnosis; and supportive care for people living with this disability. Any approaches need to be documented as they are implemented, so that the lessons learned from their efforts provide the evidence needed to drive the next stages of policy development.

A key to intervention and prevention

Accurate diagnosis of FASD is critical key for prevention and intervention. Proper diagnosis—which requires specialist multidisciplinary teams of professionals—requires capacity which is at present significantly lacking. Using data from the United States as a guide, conservative estimates suggest that the prevalence of FASD is approximately one in 100 people, and the prevalence of individuals with FAS is one in 1000. Using this estimate, the potential number of Canadians living with FAS is about 32,000, and the number of people with FASD about 340,000. At present, the number of evaluations that can be done

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annually in all of Canada is less than 2000. Such a discrepancy between the numbers of those who might require diagnosis and those who can actually get one is beyond comprehension.

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In addition to the benefits of having a proper diagnosis, population-level diagnostic information is also needed to demonstrate to governments that there is a need for services. If efforts are not made to systematically collect information demonstrating the scope of need for support services, effective and responsive systems cannot be constructed. Systems will not be built for hypothetical clients. No diagnosis—no problem. No problem —no need for a solution.

Because FASD has been constructed as a consequence of maternal behaviour and often viewed as hedonistic, reckless or self-indulgent, a diagnosis of this disability often generates a different response than other developmental disabilities that result by random chance or an undetected genetic variation. It has been (and in many instances remains) the case that the perspectives of birth mothers have been rendered invisible in diagnostic and support services for children with FASD. This has created conditions in which shame and mother-blaming have flourished, hindering opportunities for prevention within a broad range of systems. If done well, efforts to link policies and programs to enhance social supports and determinants of health, may also help to dismantle the shame and blame that underscore most contemporary prevention efforts.

The fact that many children with FASD come into contact with diagnostic and support services through the foster care system has created conditions in which it has been seen as acceptable to attribute difficulties experienced as the product of ‘poor parenting’, rather than as a result of the disability itself. Data collected systematically to demonstrate the range of impairments and support needs common to people living with FASD and their families, could also demonstrate gaps in service that could subsequently render governments accountable for ensuring needs are met.

Envision a system of screening for FASD based on alcohol exposure, facial features and most importantly on the evidence of maladaptation that appears mysterious and confusing. Those individuals screened positive would be assessed by primary triage specialists who would evaluate their history and determine

how much evaluation of temperament and mood, cognition and performance, and global environment has already been done.

Individuals could then be referred on to FASD multidisciplinary programs (that would need to be built at a pace keeping with demand). These multidisciplinary programs could then address the more challenging needs of individuals, and over time, begin to see what percentage of the problems are the direct results of brain damage, and which are social, environmental, or something else. These final clinics could be organized in a way that allows data collection for consistent, cross-clinic and cross-provincial and territorial study.

These data could also identify the specific functional diagnoses of the patients and their treatment needs. These data may also identify issues in the ways the patients were managed (via their interaction or lack of interaction with services) prior to diagnosis, which may help set targets for the prevention of secondary disabilities. When diagnosis is not linked to supportive services in a timely and ongoing fashion, individuals with FASD are placed at further risk for developing problems often described as secondary disabilities. These include poor performance in school, disrupted school experience, mental health problems, difficulty with employment and maintaining independence as an adult, as well as coming into conflict with the law (Streissguth and Kanter 1997). Data tracking outcomes for individuals seen at these clinics could help identify what types of supports reduce the likelihood of developing secondary disabilities, and also identify areas in which governments need to invest more in order to meet prevention needs. Finally, the data could help identify birth mothers, some of whom may have FASD themselves, all of whom may be at risk for future substance-exposed pregnancies.

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Achieving prevention of FASD requires policies that help us to more effectively link supports for all types of families. These data would be key to building models that would allow for appropriate planning to expand capacity for diagnostic clinics and for services for all individuals, families and communities affected by FASD.

Questions that need to be asked right now

- How much do we need to increase capacity?
- Where should new programs be located?
- Who should staff them?
- How do we monitor program processes and outcomes?

Answers to these questions come by analyzing the composition and work of programs themselves and include the following:

- Who is on the staff?
- How much time do they spend with each client?
- Do they need more time with each client?
- Could they use their time more efficiently, if so how?
- Are experiences or needs different in different places?
- Do urban services need a different composition from rural?

Some of these data can be gathered at this time through the use of a common data set and common data analysis at diagnostic clinics, supported by CanFASD Northwest and NeuroDevNet.

Clinics serving children are routinely collecting almost all this information now. However, these data are collected in varying ways and are often not kept after the evaluation is completed. A common form for pediatric diagnostic clinics is now available from the CanFASD Northwest. CanFASD Northwest's Network Action Team on FASD Prevention from a Women's Health Determinants Perspective is undertaking a similar initiative to create common evaluation and outcome measures for women-serving programs.

Evidence-based policy for integrated, supportive, and effective care

FASD requires policy responses that are meaningful, effective, and compassionate. This requires increased system capacity for interagency cooperation to support individuals living with FASD, pregnant women, mothers struggling with substance use problems, adoptive parents, foster parents, and those who provide support. To achieve this understanding, we need reliable data demonstrating the scope of challenges experienced by individuals with FASD at various developmental stages, what supports are needed to achieve positive outcomes, and what may be the most effective means of delivering these supports. Screening materials are available that could be used for a demonstration system within the confines of one or more provinces that already have reasonable FASD diagnostic capacity to increase their load to a double or triple amount over a few years time.

During this period, the work of the clinics should be analyzed so that the procedures and processes of the programs can be standardized and itemized for personnel and cost. Similar data are also needed from programs serving birth parents, foster and

adoptive families, including reliable outcome measures to identify the range of supports needed to facilitate more positive outcomes. Together, these data can provide a strong evidence base which can then be used by governments and health planners to identify models for organizing and delivering integrated, supportive care.

References

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The Research in Diagnostics Network Action Team's research carefully evaluated gaps and missing information that are necessary for providing a more accurate and consistent diagnosis of Fetal Alcohol Spectrum Disorder across clinical sites. In collaboration with NeuroDevNet, the team is preparing to work with FASD diagnostic clinics from across Canada to use the Common Data Form in a pilot project documenting the functional diagnoses and treatment recommendations made by clinics in each region. For more information contact, Dr. Sterling Clarren via Krystina Tran, ktran@cw.bc.ca.