



Intervention recommendations and subsequent access to services following clinical assessment for fetal alcohol spectrum disorders



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ABSTRACT

Background: Children with fetal alcohol spectrum disorders (FASD) and prenatal alcohol exposure (PAE) experience multiple difficulties requiring various interventions. Researchers have called for investigation into service use with respect to clinically recommended interventions.

Aims: To examine intervention recommendations for children with FASD/PAE and subsequent access to these recommended interventions.

Methods and procedures: Intervention recommendations following FASD assessment were examined for children (1–17 years). Recommendations were compared according to diagnostic status and demographic and environmental variables. Subsequent access to several interventions was examined for 45 participants.

Outcomes and results: A variety of recommendations were given. Children with FASD received more recommendations overall and received more education, anticipatory guidance, family support, and safety recommendations than undiagnosed children with PAE. Undiagnosed children received more mental health and reassessment recommendations. Older children received fewer family support and developmental therapy recommendations but more mental health recommendations than younger age groups. Many families accessed modified school programming, developmental therapy, psychiatry, child counseling, and parent support as recommended.

Conclusions and implications: Children with FASD and PAE have extensive needs and should receive individualized recommendations. An assessment is valuable even without an FASD diagnosis. Areas of high/low service access may provide insight into accessibility and perceived importance of interventions.

What this paper adds: This study responds to important research questions regarding the intervention needs of individuals with FASD. It is novel in its exploration of intervention recommendations given to children prenatally exposed to alcohol without an FASD diagnosis (rather than only children with FASD) and in its examination of post-assessment service use patterns specifically in relation to clinical recommendations.

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1. Introduction

Fetal Alcohol Spectrum Disorder (FASD) refers to the pattern of physical, mental, behavioural, and/or learning disabilities in individuals as a result of prenatal alcohol exposure (PAE) (Chudley et al., 2005; Sokol Delaney-Black, & Nordstrom, 2003). Children with FASD may present with a wide range of neuropsychological deficits including impairments in memory, attention, visual-spatial abilities, executive functioning, processing speed, intelligence, academic achievement, and language (Mattson, Crocker, & Nguyen, 2011; Olson, Feldman, Streissguth, Sampson, & Bookstein, 1998; Mattson & Riley, 1998; Streissguth, 1994). In Canada, the cost of FASD is estimated to be \$5.3 billion annually (Stade et al., 2009). The prevalence rate of FASD in Canada is estimated at 1 in 100 individuals with an average annual cost of \$21,642 per individual (Stade et al., 2009).

The fiscal and human costs associated with FASD are often attributed to a host of adverse outcomes that stem from unaddressed developmental and behavioural difficulties. These adverse outcomes include mental health issues, expulsion, legal troubles, incarceration, and alcohol or drug problems (Streissguth et al., 1996; Streissguth et al., 2004).

Although it is widely recognized that intervention research can provide answers for treating specific cognitive disturbances and ameliorate adverse outcomes, the literature examining the effectiveness of interventions with the FASD population is limited (Premji, Benzies, Serrett, & Hayden, 2007; Burd, 2007; Shalev, Tsal, & Mevorach, 2007). Typically, clinicians working with individuals with FASD use anecdotal reports and clinical wisdom in making decisions regarding secondary and tertiary prevention for clients with FASD, yet there is little support for the efficacy of the choices made (Burd, 2007). This is particularly troubling as individuals with FASD often have a history of difficulties in their lives and many unmet basic service needs (Grant et al., 2004). Additionally, a poor quality of life and higher levels of psychiatric distress and behavioural problems are reported relative to other at-risk populations (Pei, Denys, Hughes, & Rasmussen, 2011; Grant, Huggins, Connor, & Streissguth, 2005).

To address this gap, and clear need, one avenue of newer investigation has included the examination of evidence-based standards of care for children and families following diagnosis of an FASD. Jirikowic, Gelo, and Astley (2010) summarized intervention recommendations after clinical diagnosis of an FASD in a US sample (N = 120, age range = 0–16) (2010) based on a retrospective review of patient records from the University of Washington FAS clinical database. The recommendations spanned many systems of care and were relatively consistent for all children on the spectrum regardless of severity of diagnosis. Children received one or more recommendations most commonly in the category of education. Other categories where a majority of children received one or more recommendations were medical, anticipatory guidance, mental health, developmental therapy, and family support resources. They identified developmental trends in the recommendations (e.g. increasing mental health supports with age) as well as some areas of specialized support (e.g. educational interventions). The authors suggested that patients would benefit from additional assessments to guide individualized intervention efforts and stated that future researchers should investigate the success with which families access and implement the recommendations, and the perceived value of interventions recommended.

In a related view, Astley (2013) completed patient follow-up surveys with 61 patients involved in Jirikowic et al.'s (2010) study in order to examine patient access to interventions recommended. A large majority of families (89%) reported being somewhat or very successful in finding the interventions recommended to them, with 96% of these people reporting that some or all of their needs were met by these interventions. Families of adult children reported significantly less success in finding interventions and having their needs met, compared to those with children 18 and under. Although Astley (2013) answers Jirikowic et al.'s (2010) call for investigation into families' ease of access to intervention and the perceived value of these interventions, no investigator has yet examined which specific categories of interventions are most likely to be accessed, and how families' access to these interventions corresponds to the specific intervention recommendations provided following diagnostic assessment. Thus an important next step is to link clinical recommendations to service access, to ensure that assessment practices can be honed to best support functional application.

To that end, the current study builds on the work by Jirikowic et al. (2010) and Astley (2013). Similar to Jirikowic et al., we have provided a summary of the intervention recommendations given to patients at an FASD clinic in Alberta, Canada. We then extended this to investigate the difference in recommendations given to those children who received a diagnosis under the FASD umbrella ("FASD group"), and those who did not receive an FASD diagnosis but still had prenatal alcohol exposure ("PAE group"). Even without an FASD diagnosis, families receive intervention recommendations following assessment, yet it is unclear whether, or to what extent, recommendations are different for these two groups. Streissguth et al. (2004) found that early diagnosis was a protective factor against adverse outcomes in FASD, as the presence of a diagnosis may allow families to advocate for their child's needs. Therefore it is important to examine differences in intervention recommendations given to diagnosed and non-diagnosed groups (as well as not yet diagnosed groups), as it is possible that the recommendations given to those with a diagnosis may be associated with positive outcomes later in life.

We also examined whether age at assessment as well as prenatal and postnatal scores were associated with differences in recommendations. The pre/postnatal scores are indications of adverse events or exposures prenatally (e.g., exposure to drugs, genetic factors, maternal stress, and poor maternal nutrition), or postnatally (e.g., multiple placements, abuse and neglect, chronic health issues etc.) that may contribute to difficulties experienced by the child at the time of assessment (Astley, 2004). Pre-postnatal factors were examined to explore the extent to which other factors impact the choices made around services and interventions, since stress and trauma in pregnancy and in childhood can have an adverse impact on brain development.

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