

## *Fetal Alcohol Spectrum Disorder*

# **Intervention across the lifespan: where are we at and where do we need to go?**

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*Fetal alcohol spectrum disorder (FASD) is a complicated disability resulting in a diverse, high-needs population, who require a large amount of proactive resource support, but for whom there is limited evidence of what works. Therefore, there is a reluctance on the part of policy makers to invest in supports across the lifespan. Additionally, there is a growing sense that the needs of individuals with FASD must be considered through a developmental lens. Their primary cognitive and behavioural issues change over time as a result of brain development, and the changing behavioural expectations placed upon them. The goal of this document is to identify the existing gaps in research and provide an overview of the key needs at different developmental stages, and provide direction on where to go from here.*

## **Identifying the Research Gaps**

Access to effective intervention, particularly early in life, has been documented as a protective factor for children with FASD. Many professionals and service providers have worked hard to establish programming for those with FASD. However, lacking a foundation in solid research, these programs are often based on trial and error experience with individuals with FASD, anecdotal information, or programming experience originally designed for other disabilities. Beyond subjective assessment, there is limited information available evaluating the success of these efforts. Despite well documented needs, and the high costs of FASD in our communities, research into effective interventions for this population continues to lag. Calls for evaluation and research into effective interventions are still in the early stages.

There are several explanations for the research gaps. Firstly, there is a significant range of deficits identified in individuals with FASD, and no single profile defines the needs of the affected individual in a way that could direct effective interventions. Moreover, researchers have suggested that commonly used interventions addressing specific areas of deficit may not have the expected results; therefore an understanding of the unique profile arising from prenatal alcohol exposure is needed to ensure optimal intervention efforts. Thus a situation is created in which there is a diverse, high-needs population, requiring a large amount of proactive resource support, but for whom there is limited evidence of what really works. Therefore there is a reluctance on the part of policy makers to invest in lifespan supports. There is also a growing sense that an individual's needs

must be considered through a developmental lens because the primary cognitive and behavioural issues change over time as a result of changes in brain development. As individuals grow they also face increased behavioural expectations from society at large.

Secondly, there is the cross-discipline nature of FASD. In practical terms, this means that intervention efforts will likely need to cross between systems that are traditionally independent (for example Education and Justice), which creates both communication and funding challenges.

Thirdly, challenge occurs as a result of the multiple environmental vulnerabilities individuals with FASD face. Current research has focused solely on interventions targeting specific issues at an individual level. Rarely does an individual with FASD successfully cope without a wide range of services and supports. This means that any research that includes multi-tier, multi-system interventions needs to take into account interactions between the individuals, their caretakers, families and communities, as well as the environments in which they exist.

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## Key Needs Across the Lifespan

### Preschool Years

Problems in cognition, learning and memory, attention, and academic achievement have been found among preschool children with FASD. Knowing this, early diagnosis of FASD leading to intervention in the preschool years has been described as a protective factor, associated with more positive outcomes in adolescence and adulthood. Olsen et al. (2007) have hypothesized that fostering development of protective factors such as parent's level of optimism, parenting efficacy, use of specialized parenting practices, advocacy skills, and knowledge of FASD is important to providing appropriate support to a child with FASD. Models of future intervention and suggestions around advocacy, optimized support and anticipatory guidance have been put forward based on theory and knowledge of the needs of children with FASD. Research to evaluate these strategies and approaches is needed now.

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### School-aged Years

The largest quantity of intervention research has been conducted with this age group. It is well documented that school-aged children with FASD often present with specific cognitive and academic difficulties including deficits in language comprehension, reading,

spelling, math, and additionally behavioural problems that have a significant impact on their school experience and daily functioning. Interventions to address specific academic and functional needs in the areas of math, literacy, memory functioning, social skills and personal safety have shown promising results. Additional research is recommended in these areas, and in the area of medication management.

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### Adolescent Years and Adulthood

There are no validated research studies on interventions for adolescents with FASD and very few studies on interventions for adults with FASD, despite the evidence that these are particularly challenging developmental stages. During adolescence individuals with FASD often encounter extremely pronounced secondary

disabilities. Issues such as a disrupted school experience, trouble with the law, victimization, and alcohol and drug abuse have repeatedly been noted in the literature. Adults with FASD then carry the consequences of these adolescent difficulties into adulthood and continue to require high levels of support and assistance. In a longitudinal study conducted by Streissguth et al. (1996) 415 individuals with FASD were interviewed, and 83% of adults (21 years of age and older) were unable to live independently. Poor planning, poor decision making, and an inability to follow through were cited as the main issues.

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## Where Do We Go From Here?

### Animal Models

Animal models have played a pivotal role in the research of FASD by demonstrating the adverse effects of alcohol on developing fetuses. Since labelling alcohol a teratogen, research has focused on the specific targets of prenatal alcohol exposure. This has opened the door for current studies to gain better understanding and to explore protective and mitigating strategies within the social environment of those with FASD.

One of the main advantages of using animal models for FASD research is the ability to strictly control experimental conditions which, due to ethical constraints, is not possible with human subjects. Additionally, animal models have demonstrated similarities to human subjects in areas such as teratogenic influence, mother-infant early interactions, and social learning patterns, allowing many of the research questions surrounding the mysteries of FASD to be more thoroughly explored.

Research focused on the behavioural teratogenic effects of alcohol have used animal models to demonstrate that enriched environments, motor training and exercise can reduce the negative effects of prenatal alcohol exposure. Other areas of research with animal models that have produced promising results include the use of dietary interventions, and research exploring the impact of attachment and interaction patterns. Sussman and Koren (2006) suggested that these models hold tremendous promise for clinical and intervention strategy developments for individuals with FASD because many of the problems caused by prenatal alcohol exposure can be reproduced in animals.

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### Help from Other Disciplines

FASD is a complex disability, presenting challenges to researchers at every turn. Faced with questions ranging from the need to identify and understand the specific neurological brain mechanisms affected by prenatal alcohol exposure, to agreeing on common terminology for diagnosis and intervention, the most traditional approach has been to tackle these issues with an insular, deconstructive, and singular focus. However, Hyter and Way (2007) suggested that singular disciplines cannot effectively or adequately address the complex issues and needs of individuals with FASD, and multi-tier interventions that consider more than the individual are needed. Freisthler et al. (2006) recommended that research efforts must take into account caretakers, families, and communities, as well as interactions between the individual and the environment to develop more holistic strategies that are effective in real world settings.

Other disciplines, such as those focused on child abuse and maltreatment, face similar challenges to those researchers working in the field of FASD. Putnam (2003) stated that issues such as uniformity of definitions, sample size, follow up studies, and choice of appropriate comparison groups, have presented obstacles in respect to finding evidence-based interventions for issues of child maltreatment. These same obstacles are often cited in FASD research and literature. Hyter and Way (2007) suggested that it is important to examine research, interventions, and assessment practices currently being used in other countries, cross-culturally, and across disciplines, to identify aspects of these practices that may apply or can be adapted to the area of FASD research.



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## Addressing The Issues

Early research into intervention with individuals with FASD has produced promising results. These efforts have been geared towards either amelioration of primary deficits due to the impact of brain injury, as described in the animal research, or the more immediate efforts to enhance the successes through environmental adaptation and appropriate supports. Yet, as previously noted many hurdles remain for intervention researchers as they respond to the call for supports. The following strategies address some of these issues.

### 1. Increasing functional impact

In many cases interventions have targeted very specific skill sets, which have provided promising information. However, it is unclear how these discrete interventions might impact the overall functioning of an individual with FASD. Thus, ongoing research efforts will need to look to ways to begin to integrate approaches found to be effective, into larger programs of support that can be implemented at school or home levels. Success may then also be evaluated on a broader level to ascertain the effectiveness of larger systems of support. It is worth noting that no clear sense of what would constitute success currently exists.

### 2. Establishing shared outcomes

While more successes and less failure are optimal, specific outcome goals remain study-specific and therefore create challenges for broader evaluation of functional, day-to-day implications of intervention efforts. The diverse needs and situations of individuals with FASD, further complicate evaluation of outcomes, and raise the question of how to establish global outcomes that have meaning across settings and individuals.

### 3. Moving to a lifespan perspective

In the FASD intervention research reviewed, there is a substantial gap in intervention research on adolescents with FASD. This is disconcerting given the evidence that suggests that the deficits among individuals with FASD may become exacerbated during adolescence and more pronounced with age. Consequently, adolescence is a particularly vulnerable time for individuals with FASD. Adolescents with FASD also tend to display high rates of

risk-taking behaviours combined with poor decision making. The transition to adulthood can be very challenging, thus intervention research with adolescents and adults, across transition points is critical.

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## Conclusion

Although over thirty years of research has provided an increased understanding of the needs of this population, our efforts to respond to their identified needs has not yet received much empirical inquiry. Fortunately this is changing and research in the field of intervention is growing. Much remains to be done. In particular, the exploration of how existing treatments may be adapted to suit the population of those with FASD, exploration of ways to evaluate efficacy of multi-level approaches that attempt to respond to the broad range of issues present, and to explore ways to effectively translate any research into practice.

Thus it seems to be generally agreed that collaboration between disciplines will facilitate broader research that may provide insight into function across skill sets and settings. Yet the process by which this may take place is obstructed by funding and systemic issues that are deeply rooted. Interventions that may be in place through childhood are removed as individuals enter adulthood. As the field of FASD continues to grow, so must the quality and quantity of research into intervention practices. This is important so that practice can evolve towards increasingly effective approaches and that they provide the necessary evidence to support a system-wide shift in the ways we conceptualize and construct interventions. It is only through our combined research efforts that the evidence supporting best practices will be established, and the policies may be implemented that make the best use of available funds.

The Intervention on FASD Network Action Team's (iNAT) research goals are focussed on the intervention needs of individuals with FASD across their lifespan. For more information please contact team lead, Jacquie Pei or coordinator, Lori Walls, at [inat@alberta.ca](mailto:inat@alberta.ca)