


# Policy Webinar Report

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## Supporting Children and Youth with FASD: Finding our Way Together

September 24, 2021



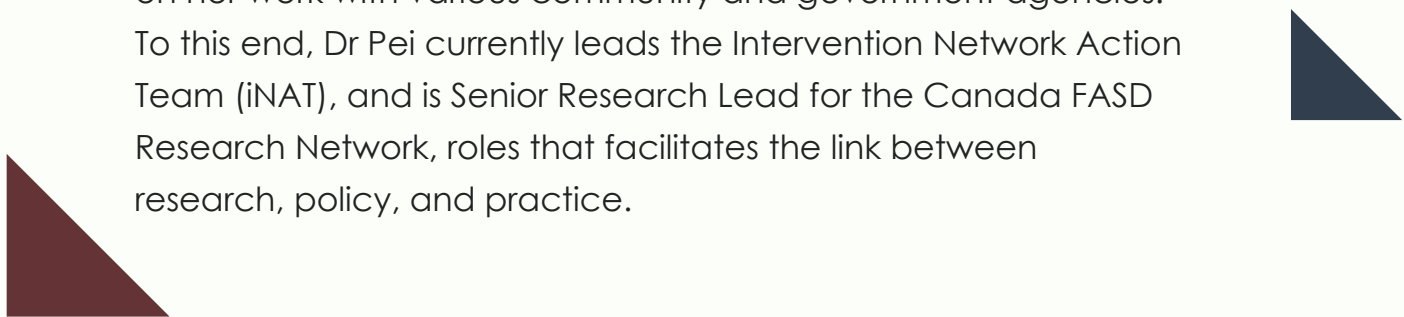


This event was intended to stimulate discussion for policy makers and enhance understanding of key elements of effective interventions to support children and youth with Fetal Alcohol Spectrum Disorder (FASD). It is important to note that this summary uses the term 'FASD' but individuals with a range of prenatal alcohol exposure who do not have a diagnosis of FASD can still present with cognitive and behavioral challenges that can benefit from interventions.

This report is to provide an overview of the webinar and summary of the policy discussion. This report is to assist you with sharing the information with others in your ministry. Canada FASD Research Network (CanFASD) is honoured to support the efforts to improve the outcomes of individuals with FASD through this webinar series. British Columbia was the lead province for this webinar. You can access the video presentation [here](#).

**Presenter:**

Dr. Jacqueline Pei is a Professor in the Department of Educational Psychology and Assistant Clinical Professor in the Department of Pediatrics at the University of Alberta. Dr Pei began her career as a criminologist and forensic counselor working with incarcerated youth. Motivated by this early work, she returned to academia to study youth at risk, child development, and neuropsychology. Now, as a researcher, and a practicing Registered Psychologist for the past eighteen years, her research focus includes identification and evaluation of interventions to support healthy outcomes for youth put at risk, and in particular individuals with Fetal Alcohol Spectrum Disorder. Dr Pei has over 100 peer reviewed publications and reports, but places the greatest value on her work with various community and government agencies. To this end, Dr Pei currently leads the Intervention Network Action Team (iNAT), and is Senior Research Lead for the Canada FASD Research Network, roles that facilitates the link between research, policy, and practice.



**Facilitator:**

Mr. Darren Joslin worked for the Government of Alberta for 31 years in the Social Services and Health sectors. His work focused on a number of different areas including Fetal Alcohol Spectrum Disorder (FASD), Mentoring and Youth Homelessness. He was the Co-Chair of the Alberta FASD Cross-Ministry Committee during the development and initial implementation of Alberta's FASD 10-Year Strategic Plan. As a member of the Canada Northwest FASD Partnership he was involved in the establishment of the Canada FASD Research Network.

## Presentation Summary

### I. The story of research

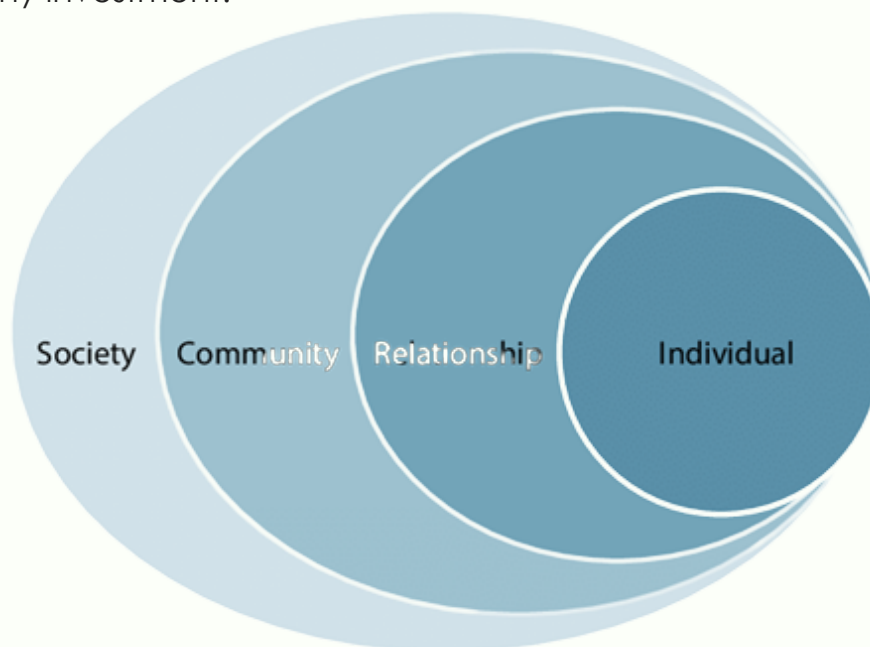
The process of intervention research for children with FASD can be slow, challenging, and take place across several years. In part, the length of time reflects the rigor of scientific research. It begins with ideas and questions from researchers, policy makers, or others in the community. It is followed by applications to acquire funding and construct an ethical protocol for research. If applications are successful, the research study begins involving participant recruitment, data collection, and data analysis, with findings eventually published and disseminated to stakeholders. Finally, if an intervention is effective in the research study, and after considering replicability and feasibility, it can be implemented in practice settings.

The goal of intervention research is to identify how we can change a child's developmental trajectory over time to optimize their long-term outcomes. This process is uniquely longer than some research, such as characterizing a child's neurodevelopmental profile at a single time point.


It demands considering the balance between expediency and rigour to ensure an intervention is both efficacious and feasible within the constraints of available resources. The generalizability and specificity of the intervention must also be considered to ensure that it is effective in responding to the heterogeneous needs of the population across settings, yet still caters to the unique needs of the individual. Lastly, enthusiasm for novel interventions in the community should be counterbalanced with scientific evidence

## II. Impact of Interventions (individual and relationships)

Currently, there is no consistent 'recipe' for an ideal intervention for youth with FASD and their families. However, there are a number of 'ingredients' that can guide us to embrace the complexity and create effective interventions targeting the individual, their relationships, their community, and the broader society (Figure 1; Pei et al., 2021). At each level, researchers have demonstrated evidence of growth after interventions reiterating that this is a worthy investment.




**Figure 1. FASD interventions can be targeted at the individual, their relationships, their community, and/or their society.**



At an individual level, there is compelling research in animal models revealing that animals with prenatal alcohol exposure experience greater neural development after placement in an enriched environment, compared to those placed in a regular environment. Children's brains are also known to benefit from enrichment, and this also applies to children with prenatal alcohol exposure. We have seen this through direct, targeted intervention with children, which has resulted in growth in a child's cognitive and behavioural functioning in many specific skill sets: self-regulation, math, and memory. Notably, an important 'ingredient' across interventions is the direct engagement of the individual with FASD, through actions such as the co-creation of strategies. This results in a personalized and developmentally appropriate approach that reflects their unique brain-based needs and captures their strengths.

Relationships have emerged as a central ingredient within intervention research, with the goal of increasing healthy, nurturing, and resilient children and families, in essence thereby nurturing all aspects of an enriched and growth-promoting environment. This can include increasing parenting capacity through educational resources, facilitating an understanding of behaviour regulation within children and caregivers, increasing stability for children within caregiver placements, and taking proactive approaches to supporting children across the lifespan. Relational approaches used within programs, such as mentorship and success coach models, are additional examples of ways to provide these supports to children and caregivers.



### III. Impact of Interventions (community and society)

At the community and society level, we do not have high fidelity intervention studies yet. However, there is a published document 'Best practices for serving individuals with complex needs' (Pei et al., 2018) to provide some guidance. Within this guide four overarching principles are provided, to help guide our approaches to service delivery. First, consistency within an agency to ensure that all staff are well-trained and well-supported to facilitate shared messaging and congruent approaches to support is critical. Second, the collaboration between organizations or agencies providing support is necessary to foster interdependence and integrate multiple sectors of services such as education, health, and employment for children with FASD. This requires intentional and embedded opportunities (e.g., allowing time for phone calls) for frontline service providers or other staff to build, and work with, those connections. Third, responsiveness is important to work with children with FASD and their families to create proactive and tailored solutions. Lastly, proactivity promotes a lifespan approach to facilitate service continuation and planning well into the future. To be feasible, these principles need to be present at a policy-level for the organization and realized at a practice-level for the individual.

Research can occur in many ways - it entails a systematic and organized approach to answering a question. At a community level, this can be enacted through evaluation activities that may allow for acceleration of intervention service delivery, while accountability to outcomes is maintained. Others may pursue applied research or community-based participatory research. These approaches can be valuable in identifying what meaningful outcomes are for an intervention, determining what cross-cutting themes exist across diverse interventions (critical 'ingredients!'), and considering how formative feedback can improve programming.

These approaches to research and inquiry support efforts to action an integrated approach towards growth and healthy outcomes for children with FASD and their families.



**Figure 2. Each of domains can be addresses by interventions across an individual's lifespan to promote healthy outcomes for an individual with FASD.**

# Themes From Discussion

*1. The voices of youth with FASD and their families should be considered in intervention research and policy.*

As active participants, their voices can play a role in creating individualized strategies, reducing stigma, and increasing a sense of autonomy and control for individuals with FASD and their families. Strategies tailored to an individual's unique needs can foster authenticity, interdependence, and adaptability across the lifespan. Protective factors in the individual and their environment can also be identified to promote strength-based approaches, resilience, and healthy outcomes. Lastly, it should be considered that when individuals with FASD and their families are partners in the process of intervention research and policy, it can be arduous for this vulnerable population.

*2. Staff training, supervision, and retention should be considered a priority.*

Staff need to be empowered with knowledge and a range of effective tools around FASD interventions through ongoing training. This includes being FASD-informed, trauma-informed, and stigma-aware to build relationships with youth in a responsible and caring way. The goal is to increase staff capacity and self-efficacy, as well as foster reasonable expectations for growth and accountability at work. Additionally, maintaining collaboration and connection with supervisors can help to discuss successes and challenges, feel heard and protected, and find the courage to try something new. Staff retention is also critical. Relational approaches are particularly effective with children with FASD, however, if a staff member leaves after building a relationship, this can become another loss and traumatic experience for the child.



Through effective training and supervision, staff can be more responsive to the unique needs of children, willing to take on new clients, and establish stable relationships that persist through transitions.

Comprehensive training (<https://canfasd.ca/online-learners/>) and guidelines around best practices ([https://canfasd.ca/wp-content/uploads/2018/09/Best-Practices\\_June12018.pdf](https://canfasd.ca/wp-content/uploads/2018/09/Best-Practices_June12018.pdf)) for FASD can be accessed through CanFASD.

*3. Individual complexity can be reframed to highlight opportunities for collaboration and growth.*

There is tremendous variation in neurodevelopmental profiles of children with FASD, with the added impact of trauma and marginalization (Flannigan et al., 2020a; Flannigan et al., 2020b). These compounding experiences can contribute to poor long-term outcomes; however, complexity does not equate to inevitability. Instead, we must embrace the complexity and use innovation and collaboration to create interventions that promote healthy outcomes for children with FASD (Pei et al., 2019). A specialized stream of services for FASD is not always required, but service providers must adapt their approaches and expectations accordingly as interventions tailored to individuals with FASD are linked to more consistent, positive outcomes. Although the range of risk is greater with complex disorders, so is the range of benefits. When we begin to ask “how” success might be accomplished, we open the door to new possibilities for growth. In this way, complexity can be reframed, not as a barrier, but rather as an opportunity to embrace innovative and creative approaches to leveraging individual and community strengths as we support healthy outcomes for all children.

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# References

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4. Pei, J., Poth, C., Tremblay, M., Walker, M., 2021. An Integrative Systems Approach to Enhancing Service Delivery for Individuals with Complex Needs. Current Developmental Disorders Reports, 1-12.
5. Pei, J., Tremblay, M., Poth, C., El Hassar, B., Ricioppo, S., 2018. Best Practices for Serving Individuals with Complex Needs: Guide and Evaluation Toolkit. PolicyWise for Children & Families in collaboration with the University of Alberta.



Hazel is a 9-year-old who has FASD. She loves art and really enjoys painting, drawing and making things out of clay.

*Used with permission from CanFASD's 2021 Art Competition.*