

Webinar Report

FASD and Mental Health and Wellness: Urgency, Recognition, and Solutions for Government Policy Makers

February 13, 2023



The purpose of this event was to stimulate discussion for policymakers and to enhance understanding of the opportunities and challenges of reducing stigma for individuals with FASD, their families, and support systems. Dr. Jacqueline Pei provides us with a framework to think about people with FASD and wellness as well as mental health. Dr. Kelly Harding shares work on recent research on the suicidality within this population.

This report is intended to assist you with sharing the information with others in your government. The Canada FASD Research Network (CanFASD) is honoured to support the efforts to improve the knowledge and possible solutions to reducing the stigma in this field.

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.

Presenters:

Dr. Jacqueline Pei – 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. Also, a practicing Registered Psychologist for the past twenty years, Dr Pei began her career as a criminologist and

a forensic counsellor working with incarcerated youth. Motivated by this early work, she returned to academia to study youth at risk, child development, and neuropsychology, leading to her current focus on interventions for individuals with Fetal Alcohol Spectrum Disorders. Dr. Pei has over 75 peer-reviewed publications 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) for the Canada FASD Research Network a role that facilitates the link between research, policy, and practice.

Dr. Kelly Harding – Dr. Kelly Harding is an interdisciplinary feminist women's health and disability scholar. She received her PhD in Interdisciplinary Rural and Northern Health from Laurentian University in Sudbury, Ontario, Canada. Kelly is the Director of Research Administration and a Research Associate with the Canada FASD Research Network. She is also an Adjunct Faculty member in the Department of Psychology at Laurentian University. She has worked in the field of FASD since 2010 and is involved in diverse research projects in the areas of FASD prevention and women's health, FASD assessment and diagnosis, family well-being, social media, mental health, and human rights.

Pre-reading material:

[FASD and Adversity Issue Paper](#)

[FASD and Suicidality: Rates and Associated Factors](#)

Attachment:

FASD and Mental Health Vignette

Summary

FASD is a disability that is often underrecognized and misunderstood. Considering promoting quality of life for everyone requires several perspectives and approaches. This presentation tackled the mental health and wellness of people with FASD from an ecological perspective of individual, relational, community, and societal levels. This presentation explored what the literature says about the presentation of mental wellness and illness for this population, and then expanded our view to think of policy considerations from several vantage points. Key considerations included thinking about how to better serve those with FASD who are unwell and what they need, but also balancing the support and leveraging the resiliency and strengths of individuals with FASD. The presenters framed these considerations around the United Nations Convention on the Rights of Persons with Disabilities and within an ecological framework to think about how we can make large societal shifts to better support home, community, and familial support systems, while also considering their overlapping and intersectional nature.

Presentation

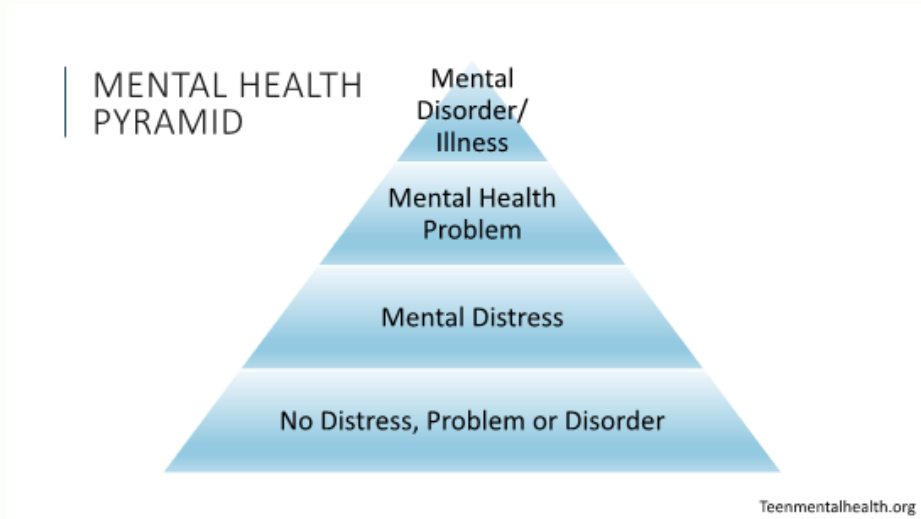
Mental and FASD

What is Mental Health?

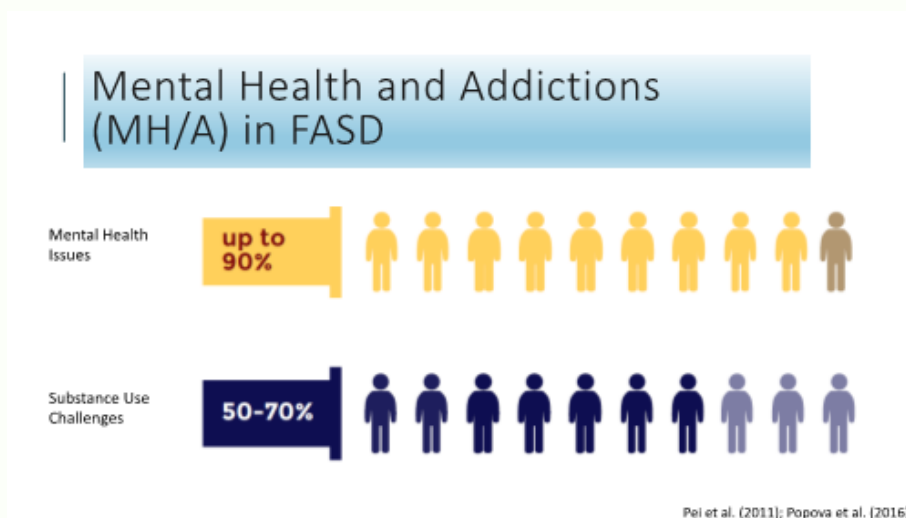
World Health Organization says

“...a state of well being... an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively, and is able to make a contribution to his or her community.”

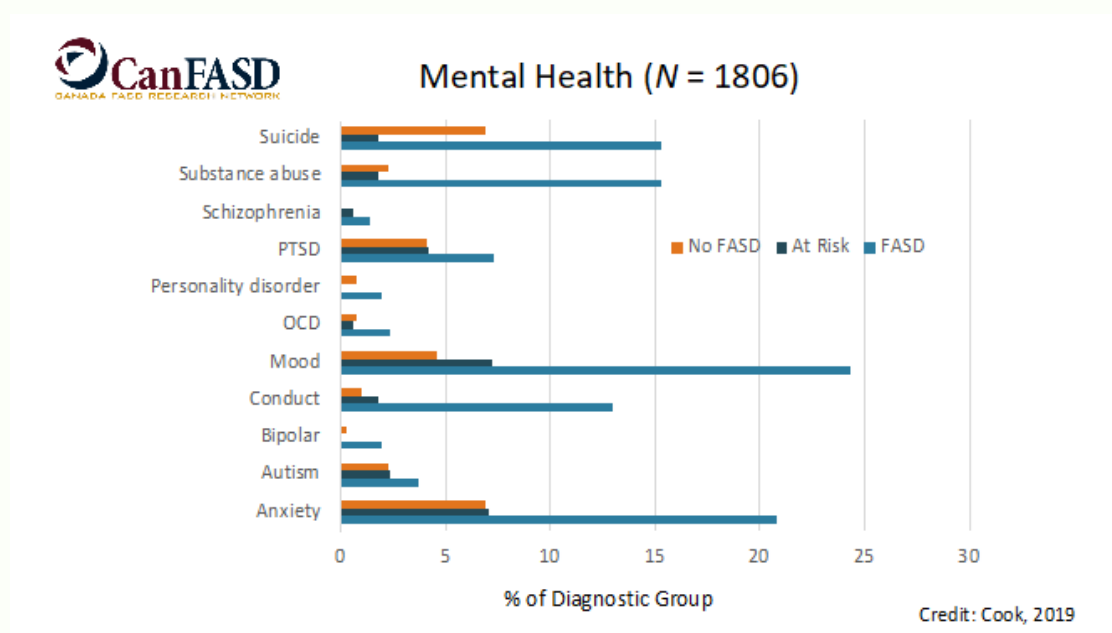
“more than just the absence of mental disorders or disabilities”
 ...not only avoiding active conditions but also looking after
 ongoing wellness and happiness.



Most people on a day-to-day basis have no distress. Mental distress would be common stressors that we respond and adapt to such as taking a test. Mental Health problems may have a larger impact or persist over a longer period of time such as the death of a loved one. Mental Disorder or Illness would be a diagnosable condition that requires ongoing treatment. These conditions/levels can co-exist and can have multiple response strategies. Thinking about each of these stages and our policy responses, strategies, or responses will help us to frame the work, leading to improved quality of life for all individuals.



What we know about FASD and mental health specifically includes very high rates of mental health challenges. However, it is also important to consider the alternative perspective (i.e., strengths-based as opposed to deficits-based) to understand how we can leverage strengths for individuals with FASD who are not experiencing mental health issues, what supports and services they are accessing, and what the protective factors are for them. What are we doing well and how can we develop this further? When do we need to intervene? What are the different points in time that families need support across the life course?



This information on mental health conditions experienced by individuals with FASD comes from the National FASD Database. There is a broad array of co-occurring conditions. In looking at mood disorders, there is a high prevalence of these conditions within the FASD population of about 25%, however, this also means that 75% did not have a mood disorder. How can we leverage this positive?

Suicidality refers to suicide related concerns including thoughts, ideation, talk, attempts, or death by suicide. Suicidality within the FASD population is quite high. From the National FASD Database, ~25% of individuals had experienced suicidality at some point in their lives. When we break this down by age, it is a concern across the lifespan but particularly troubling among transitional aged youth and young adults. What might be unique or happening at this stage in life for individuals with FASD? Some concerns may include teenagerhood, puberty, peer pressures, siblings and other familial concerns, etc. – what does this mean for how we respond at different timepoints across the lifespan?

**“A lot of people don’t want to die
– they just don’t want to live.”**

A quote from a participant in our research. This example speaks to the challenge of wanting to live a good life but feeling that they can’t because of the lack of support, services, family connections – sometimes it may be easier to give up.

FASD AND MENTAL HEALTH

Convergence of genetic, environmental, and neurophysiological factors produce a complex picture.



(Pei et al., 2011)

Mental Health for people with FASD is complex and we need to consider the genetic, environmental, and neurophysiological factors when designing programs or policy for this population.

Response considerations

Social Ecological model to consider

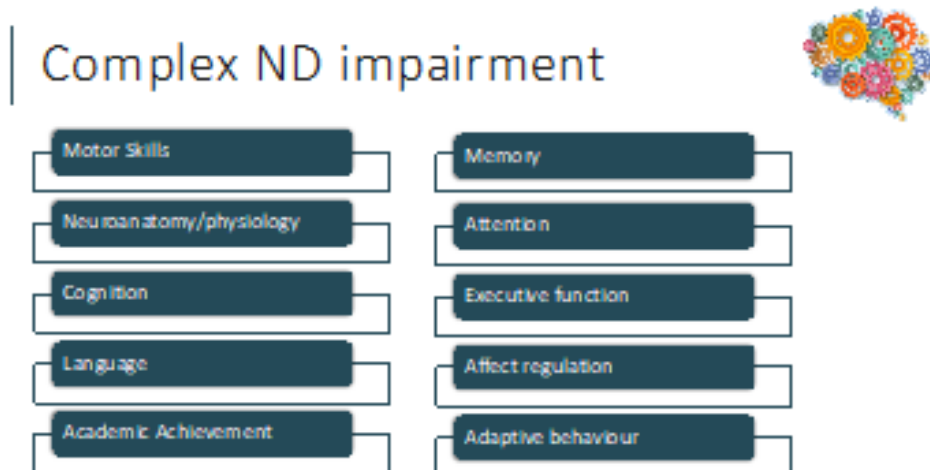


These levels are overlapping and interconnected but this framework is a way to break down some of the discussion into manageable pieces to consider for policy implications.

Individual

- Shared understanding the unique brain
- Balanced with the storyline of success

FASD assessment and diagnosis can facilitate supports needed. The following are the brain domains that are assessed during the FASD diagnostic process that provides a picture of the abilities and strengths of each individual. Understanding the brain matters to building the right intervention model.



These unique individuals may interact with stress in different ways. These brain impairments, coupled with an environment that may not be the right fit, can create significant stresses for individuals that are considered a cognitive vulnerability. Therefore, individuals with FASD may experience more stress when interacting with different systems such as education, housing, employment, or other daily tasks. Their brain has a more sensitive response system to that stress. They can feel the stress more acutely and intensively and it is more likely to impact them. How do we increase that good environmental fit? How do we reduce that stress level so that we are not engaging that stress response

system? This stress is further complicated when the presentation of the individual with FASD can include substance use/misuse and other unhealthy coping strategies.

The opportunity in wellness is that people with FASD have resiliency factors. What are the characteristics, environmental, or individual pieces that impact resiliency for people with FASD? One study has shown that the relational resources (e.g., strong relationships with individuals with FASD) can make them feel more capable and can help them engage better and stronger. Families see that they can engage in these relations and when we leverage these relationships, we see better outcomes. For policy, how do we tune into meaningful relationships for services and supports?

While we highlight the vulnerabilities, we must also balance and highlight the strengths and capabilities. How we manage stress for the individual and the environment is important. Elements of quality of life and wellness are situated in perceptions of one's own competency and capacity to contribute to the world around us. Creating space for the strengths puts us in a position to evaluate wellness outcomes versus mental illness.



These strengths can be capitalized on to provide effective supports.

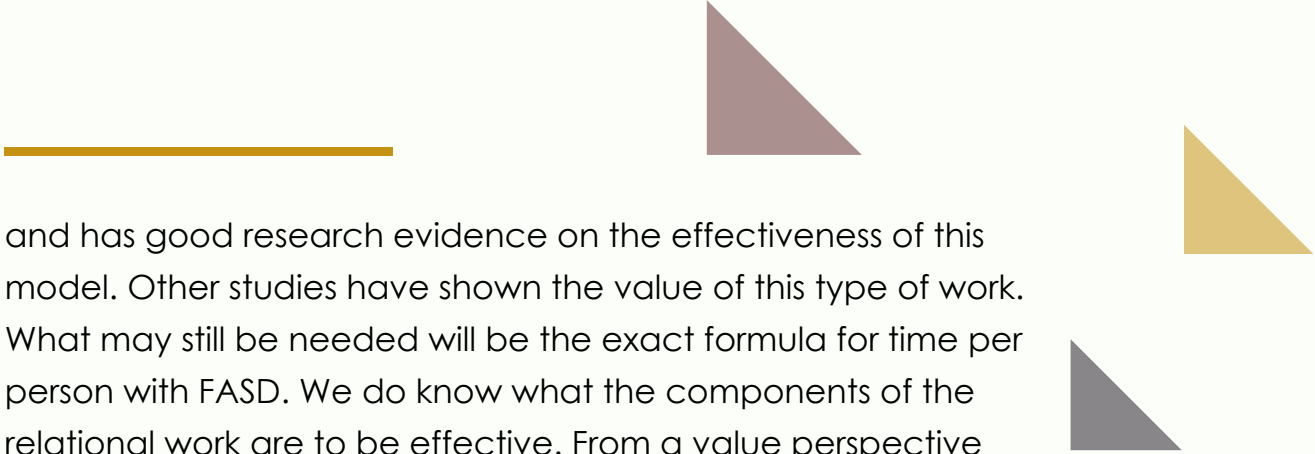
Relational

- Family stability
- Embracing relational approaches to service delivery

Individuals with FASD have significant exposure to adversity in their young lives growing up. One study looked at an average age of 9 year olds who had at least 3 adverse childhood experiences (ACEs). This is a high number of childhood experiences. We know that the higher the number gets the more likely people will experience more adverse outcome such as mental health, substance use, housing issues, criminality, etc., later in life. This should alert us to a population that is at higher risk, with understanding that their brains are at higher sensitivity to stress. How do we promote stability for these children/families? How do we reduce adversity? How can systems, such as child protection services, be FASD-informed?

When we do improve relational programs and increase family stability we can see healthy impacts. When parents have a good understanding of how their kids' brains work, they can adapt and build interventions that make sense, which further builds better outcomes for the child and family. Relational approaches can apply to other systems as well, such as schools. How do we build integration of services using a relational approach?

Relationships with the individual's entire support system is valuable. Thinking about the time commitment involved in a relational approach versus serving more people. Does the evidence support this? There is good research demonstrating that relationships matter and when these relational supports fall apart we see the reduction in the stability for the person. In the prevention of FASD, the PCAP model uses a relational model




and has good research evidence on the effectiveness of this model. Other studies have shown the value of this type of work. What may still be needed will be the exact formula for time per person with FASD. We do know what the components of the relational work are to be effective. From a value perspective versus the time component, the central tying feature to the FASD is having a trauma-informed space. One study on housing supports for people with FASD found that relational work was important for the individual but also for their family to keep the person safe.

Utilizing technology to keep families connected and supported can also be useful. What is the opportunity for a relational space?

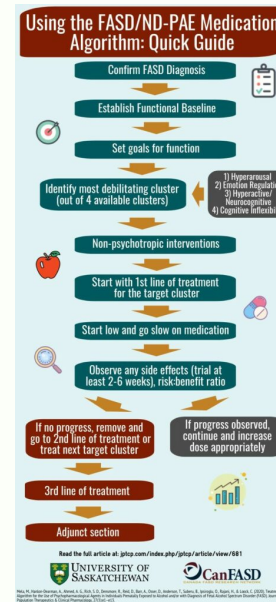
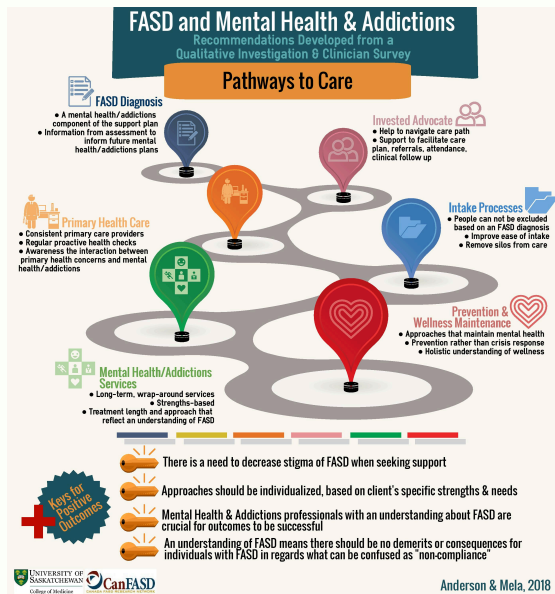
Community

- Education and training
- Integrated and responsive systems

When we have late diagnosis and assessment, disconnected service delivery, non-FASD informed providers, and lack of personal or family connection, these can all lead to poor outcomes for individuals and their families, including mental health challenges.



Two examples of collaborative knowledge translation work from Dr. Mansfield Mela's research which includes lived experience in the work.



Exploring the pathways to service can be a valuable tool in determining policy and service change needs. Medication uses this resource as part of the psychotherapy approaches, and how can we train clinicians about FASD through this resource. Common shared understanding or training can be important for people working with individuals with FASD to have the best outcomes.

It is also important to look at the contextual pieces and social determinants of health to consider the mental health prevention and needs. Do people have meaning and purpose or safety in their lives? Creating proactive solutions rather than reactive strategies is critical, and service delivery needs to be FASD informed in a consistent and evidence-based way. Can training be improved, required, and/or mandated? How do we change the curriculum for new professionals? How do we engage regulatory bodies to increase FASD training requirements?

New issue paper: Broad approaches to psychotherapy for individuals with FASD.

Societal

- Stigma reduction
- Equitable access

Inclusion and humanization of all people is the goal. In the context of people with FASD this includes stigma reduction and equitable access to supports and services.

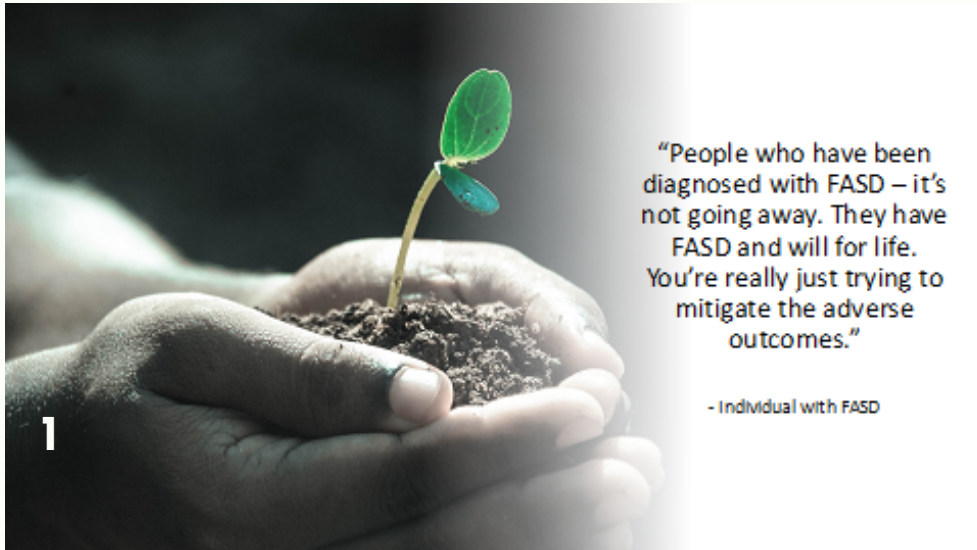
Individuals with FASD and Experiences of Stigma Issue Paper: Hearing first-hand accounts of stigma can help us to empathize and understand where systems may change.

Standard Definition of FASD: It is important to have consistent language in a positive, strengths-based way, as common language can improve our understanding and reduce stigma.

Attending to the way that we as a society treat those around us; approaching others with empathy and understanding. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) can be a helpful framing for discussing and considering FASD. Another important societal consideration is in thinking about how this involves and supports people with FASD within the broader disability community. The UNCRPD provides an opportunity to include the voices of individuals with lived experience to inform and improve policy at a national and provincial/territorial level so that people with FASD can have better outcomes.

Next steps/questions

From the voice of individuals with FASD and caregivers gathered from several different research projects.



Hope...he has connected with adults on the spectrum...they have shown us that **with direct support the sky is the limit.....**

I am excited about the **growing awareness** around FASD and **hopeful** that my kids will live a full life.

I am **excited by her finding her joy....** seeing her grow in confidence, self acceptance, and love of life, I am excited for all the adventures that lie ahead.

I am good at self care, research, finding a social support network around FASD, and most importantly I am **committed to seeing this through in the best possible way I can.**

He never wonders if he is **loved.** He is secure in that

We have a big and great **social support network.**

I love her fiercely and I will always be in her corner. We both have a great sense of humor and I trust that, and our deep love will carry us through what ever lies ahead.



RECOMMENDATIONS

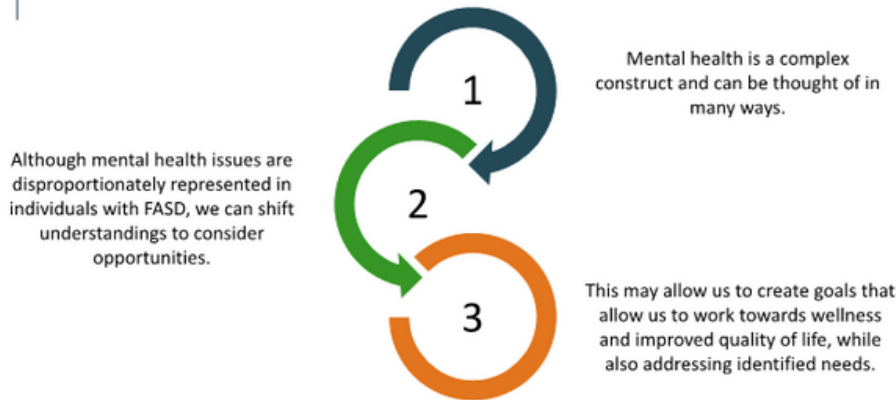
Screening/early identification of contextual and protective factors related to mental health

Comprehensive assessment of biopsychosocial needs, vulnerabilities, and strengths

Access to timely and well-suited supports to promote mental wellness and reduce factors contributing to mental health concerns and suicidality

Broad stigma reducing initiatives across the lifespan for individuals with PAE and FASD

TAKE HOME MESSAGES




Vignette

This vignette was developed from a research project on suicidality and are an amalgamation of the stories of five real families and their experiences.

Please consider the following questions as you read this vignette. Additional questions are presented within the vignette.

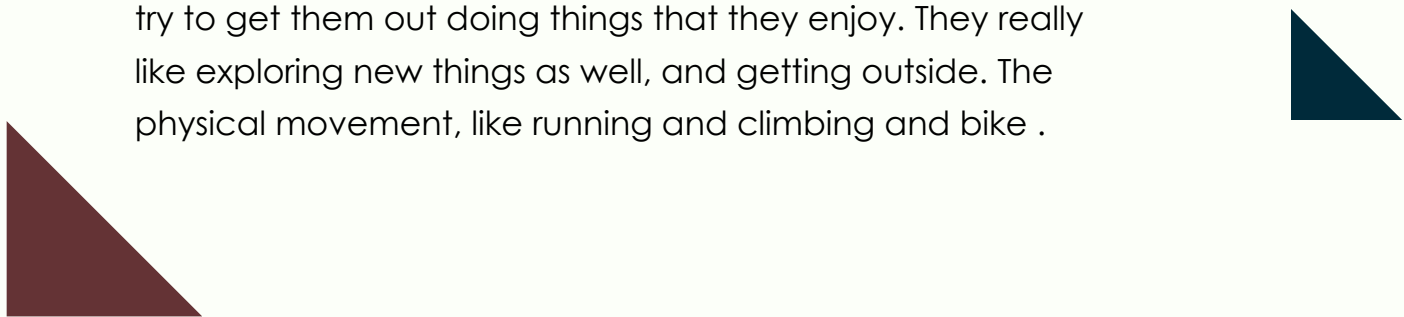
1. What individual, relational, community, and societal level factors stick out to you in this narrative? How and why are these factors important in the context of FASD and mental health?
2. How can we support mental wellness for individuals with FASD and their families? What policies are needed to support mental wellness and to mitigate these contextual factors? What is your role in supporting these initiatives?


My child has expressed feeling depressed since they were about 7 years old and that feeling has never really left them.



Their life has been really, really hard. They came from a very traumatic background before they came into our lives. They have a number of siblings, all of them who are on the spectrum. Some diagnosed with FASD, some undiagnosed, but there's no doubt in my mind. Their mother passed away when they were a child, and their father has been in and out of their life. Their father has bailed on them more times than I'd like to count. They have diagnoses of separation anxiety, oppositional defiant disorder, borderline personality disorder, attention deficit hyperactivity disorder, bipolar disorder, intermittent explosive disorder, and learning disabilities, all on top of the FASD. They have also struggled with alcohol and drug use, especially during their early teenage years. They were sexually assaulted when they were a child by an extended family member from their birth family. Their siblings would call on them and ask for money, or tell them to get back into contact with their birth father, and so that always ended up being really traumatizing and triggering. They didn't have that kind of loving support that they deserved and should have had, and so it was during those times that they ended up using alcohol and became addicted to crystal meth....these complex life experiences led to their suicidal thoughts and behaviors.

We work really hard to refocus them and distract from the thoughts when we see the volatile emotional swings. We worry that they are getting closer to the thoughts that would actually. . . lead to the end of their life, but we try to focus on the fact that it's very much in the moment. For now, we really just try to focus on their strengths and to try to get them out doing things that they enjoy. They really like exploring new things as well, and getting outside. The physical movement, like running and climbing and bike .

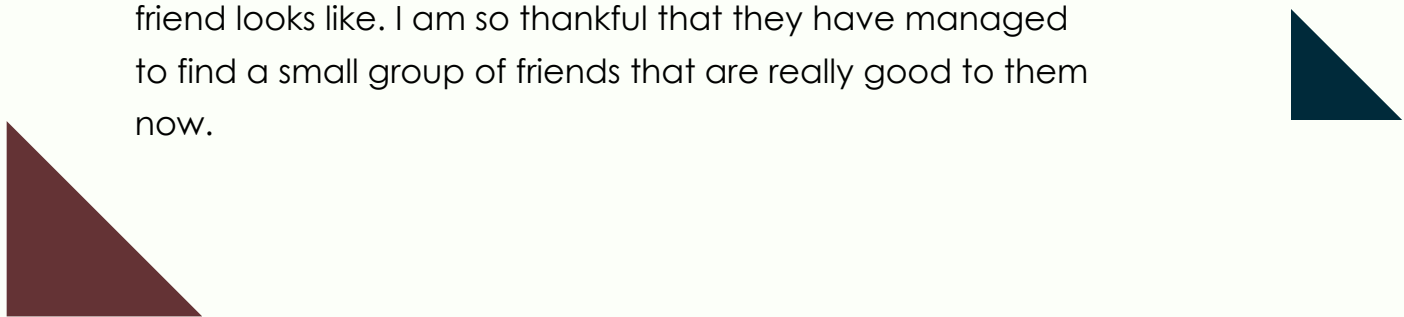


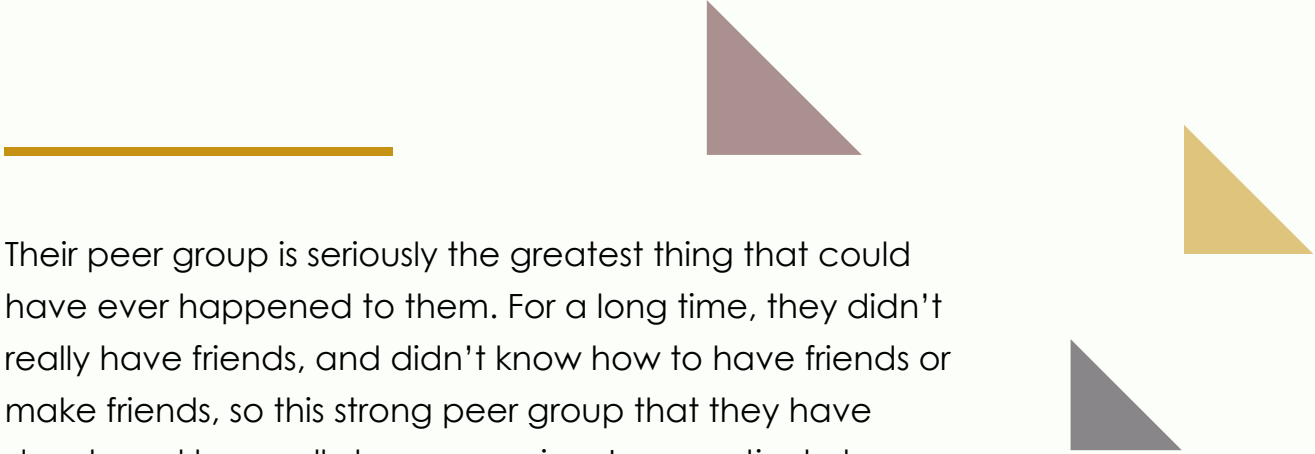


riding is really good for them. The biggest positive and help is if they get outside. If they are stuck in the house too long their mental health state just deteriorates.

For my child it is all relationship based. The relationships with peers and friends, romantic partners, and family members have such a big impact. The most recent challenge has definitely been related to school. Because of overcrowding in the town where they went to school, they were taken out of school and put in high school. That was really hard at the time because they were not really 13 or 14 mentally, their social or emotional age was maybe 9 or 10. They have experienced so much bullying at school during their life and I think a lot of that is related to their personal characteristics—their identity, their appearance, and also their developmental capabilities. They've had teachers, principals, students, even community members bully them.


In elementary school they were also teased remorselessly at school. They were quite a bit bigger when they were younger, and kids used to tease them for being fat. One time two boys put sticky notes on their back saying "I'm fat and I'm stupid" and they walked around school like that. Other kids used to ridicule them and then be like "Come play soccer!" Then the kids would kick balls at them. I would tell them that the kids were being mean, but they would say "They're my friends." And I would have to say, "No sweetheart, they're not, they're being mean to you." So, for a long time it really was teaching them and reminding them what a friend looks like and what somebody who is not a friend looks like. I am so thankful that they have managed to find a small group of friends that are really good to them now.





Their peer group is seriously the greatest thing that could have ever happened to them. For a long time, they didn't really have friends, and didn't know how to have friends or make friends, so this strong peer group that they have developed has really been amazing. I am particularly grateful for their closest friend from this peer group who intervened when they were worried about my child. A few months ago, my child said to this friend that they didn't want to be here anymore and they kind of started saying goodbye to their friend. This friend went straight to their mom and showed their mom the texts from my child, and within a minute this mother called me and told me what was going on. So probably within 5 min of that text message of my child saying goodbye to their friend, my husband and I were downstairs intervening. We didn't take their phone away, because clearly that was the tool that saved their life and I'm not going to punish them for saying they need help. So really this peer group has been so important for them in a lot of different ways.

Despite the stressors, one thing we really try hard to do is to always go over to them, always give them hugs and kisses, and tell them how much we love them. It can be hard sometimes, but we always want them to know how much and how deeply we care about them. They do have an older sister, our biological daughter, who is almost 30 now, but hanging out with her can be really good. They are super attached to her. So that's been really good for them to hang out with her.




Overall, we've had very negative experiences seeking help which has been so unfortunate because we actually moved just so that my child could get support.

1. What do you see as the role of your ministry in supporting the individual and relational factors discussed here and in the vignette?
2. What do you see the role of your ministry being in supporting the individual and relational factors discussed here and in the vignette?
3. What initiatives can you identify as being particularly helpful in addressing these individual and relational concerns?
4. What gaps do you see that could be opportunities for intervention and support?

When it comes to medical professionals, that has been a real challenge. I'll do whatever it takes to keep my child safe, but I have a lot of trepidation about the medical system. I have a lot of fear and a lot of distrust of the medical system, so I have to say it would be an honest last resort to take them to a hospital. I would really try everything in my power to keep them safe before it got to that point.

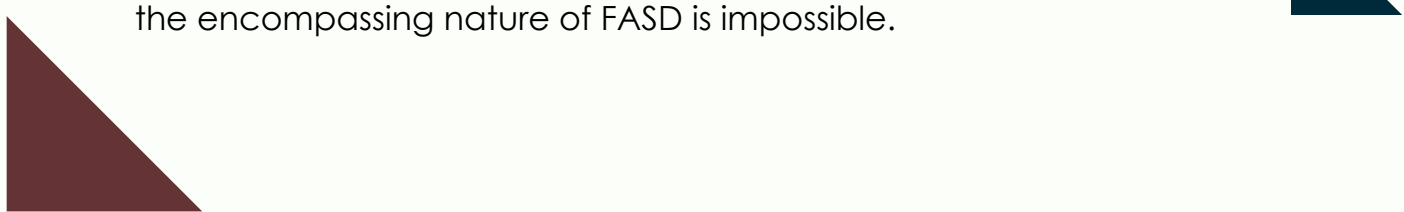
We're having a hard time getting them in to see a psychiatrist right now, but I definitely want to get them help. I just want to get them general therapy help for sure. They would do really well with therapy one-on-one and having to actually go to therapy. We were trying virtual therapy earlier this year but this Zoom therapy just does not work for them. So we had to stop that because every time it was a fight and they would just yell "no, no, no, I'm not doing

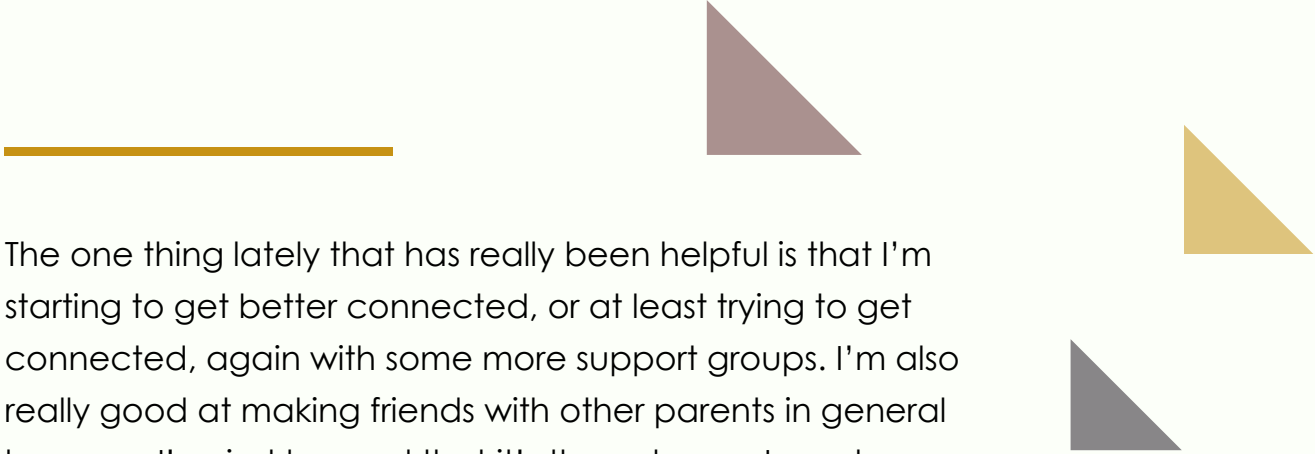


that!”. I can only push so much before I shove them off a cliff and they won’t talk to me about anything, so I’m really trying to balance respecting their boundaries vs. pushing them still a bit.


We do also have a respite worker, but the respite worker is terrified of them. Even if we could get the respite support going, access has also been a problem. It’s been very short, like 8 hours a month. That’s not enough for FASD. When the worker comes, it almost triggers them more because it’s so little. They need a constant routine and from 1 week to the next is huge in their brain because of their memory challenges. So when there is no consistency, that throws a wrench into it. It makes it worse and then it triggers them which can make them very angry and then we go down a whole rabbit hole. . . Support is really something that we have been thinking about a lot lately because we’ve been thinking about the big picture, not just the everyday day-to-day. I hope that eventually we will get something consistent and helpful for them because their situation and their challenges are lifelong, and we need to set them up for the lifelong, not just the day-to-day.


Along the way there have at least been a few professionals who have been helpful. My child had a few amazing teachers along the way who were very, very good. They also had a really good advocate at the school who was a coach. But really, I think we need more people who actually know about FASD and know how to help. There is such a lack of support for FASD and it is so encompassing. It’s not just one issue—it’s their mind, it’s their body, it’s everything—and trying to find somebody that can address the encompassing nature of FASD is impossible.





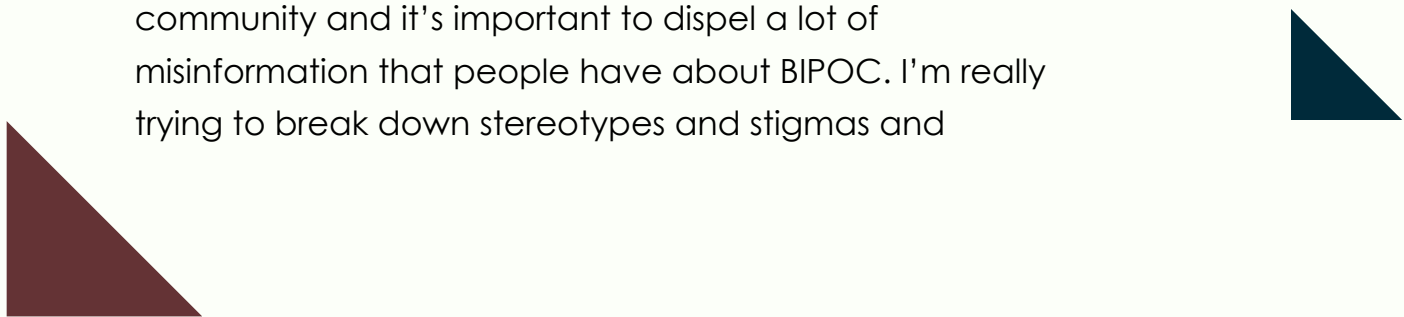
The one thing lately that has really been helpful is that I'm starting to get better connected, or at least trying to get connected, again with some more support groups. I'm also really good at making friends with other parents in general because I've just learned that it's the only way I can keep my child safe. I'm a very loud and outspoken advocate for my child. For example, because of all of the bullying at school, I made the school have a safety plan in place before I would send them back to school and I was not very pleasant about it. I was pretty harsh with the school because they are very aware of their disability, they are very aware of their struggles, and I just felt like they were not participating in keeping them safe. I have really tried to build this village around them to make sure that they are safe, supported, and understood.

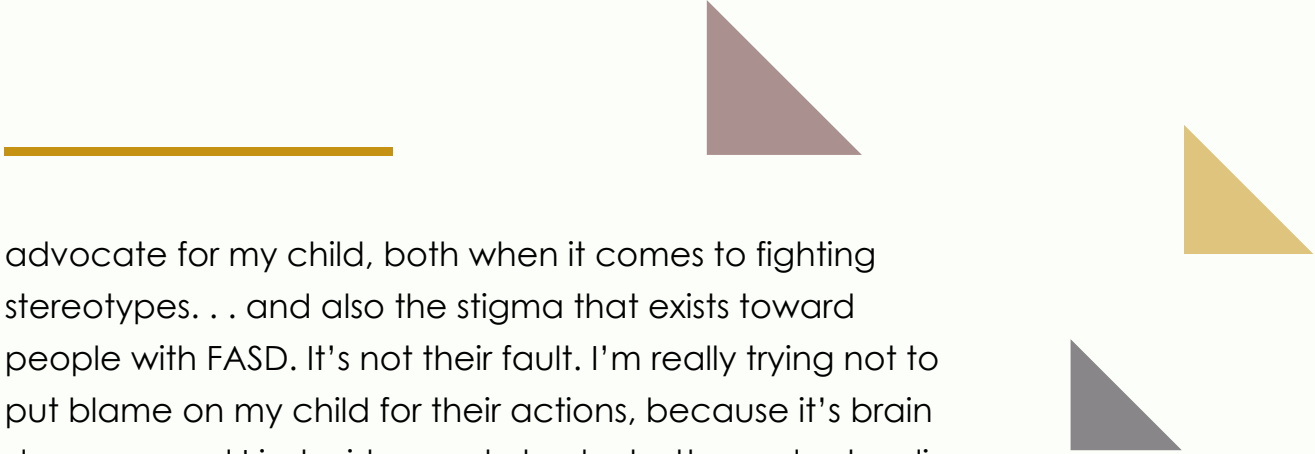
1. What training is currently provided? How well do you see training accessed and embedded in your ministry? What examples can you share that speak to these interactive and intersectional considerations?
 2. What can cross-ministry collaboration and communication look like to respond to community-level considerations? What would it look like to get there? How can we do better?
- 




The pandemic has definitely exacerbated things for our family. These emotional outbursts, the daily suicide talk. . . Since the pandemic, it's definitely increased. "You want me dead, you don't want me alive, I want to be dead", those types of things. But I think all kids are feeling that kind of languish right now, you know? That feeling like you're trapped and all you can do is walk the same circle, over and over again. One of our go-to activities as a family before the pandemic was swimming. We would swim at least twice a week and that is their one sense that just helps them get released. A bathtub is not the same as a swimming pool. So not having access to a swimming pool was very detrimental to their mental health. The lockdown definitely made things worse, but I'm also kind of grateful that it happened because it opened up the conversation for us. It's kind of a double-edged sword. I'm grateful and I'm hateful, it's kind of both. But that's the joy of living in this reality I guess! It's like that Disney Pixar movie, Inside Out. You can have multiple feelings at the same time, you can be happy and sad and mad and hateful all in the same moment and that's what I was feeling.

Beyond the pandemic, the other thing that I worry a lot about is how the world will continue to respond to and treat our child. Our child is also a member of a racialized group, so we talk a lot about what it is like having a dark dad and a white mom and the risks those carry in the world. We're not ones to go and lock ourselves on a door or anything, but we're activists. We carry an activist heart. We're always striving to improve the community and it's important to dispel a lot of misinformation that people have about BIPOC. I'm really trying to break down stereotypes and stigmas and





advocate for my child, both when it comes to fighting stereotypes. . . and also the stigma that exists toward people with FASD. It's not their fault. I'm really trying not to put blame on my child for their actions, because it's brain damage, and I just wish people had a better understanding of FASD.

1. What tangible action can we take to engage in stigma-reducing activities based on the things we have identified and talked about today?
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