

Sensory Processing and Fetal Alcohol Spectrum Disorder

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KEY MESSAGES

The way in which our brains receive and organize sensory information has a significant impact on how we interact with the world and navigate daily activities. Prenatal alcohol exposure (PAE) can lead to brain- and body-based differences that substantially alter the way an individual processes sensory information. However, sensory processing differences in people with FASD are understudied, and very little is known about how these differences may change with age. Despite this lack of research, individuals with FASD and their caregivers often describe the significant impacts of sensory processing differences on daily life and emphasize the need for more work to identify and support sensory needs related to FASD.

Issue:

Sensory processing (SP) refers to how our brains organize sensory information through taste, touch, sight, smell, balance, and internal sensations, and how we respond to that input. Challenges with SP can contribute to difficulty in many areas of an individual's daily life, such as adaptive and executive functioning, social skills, academics, and cognition [1]. Many individuals with fetal alcohol spectrum disorder (FASD) and their families report difficulties with SP, but empirical data in this area is relatively limited [2]. Although there is emerging evidence that many young children with FASD experience SP differences [2-4], very little research exists that helps us understand SP differences among people with FASD across the lifespan [2]. Importantly, there is also a notable lack of research on interventions to support the sensory needs of people with FASD.

The purpose of this issue paper is to describe current research on the rates, patterns, and correlates of sensory processing differences among people with FASD across the lifespan. Implications of sensory differences from a lived experience perspective will be emphasized.

Background:

The ways in which our brains receive, organize, and integrate sensory information impact how we engage with our environment [1]. Sensory information is received through eight systems. The five most recognized systems include auditory (sound), tactile (touch), visual (sight), gustatory (taste), and olfactory (smell), and we also have three internal sensory systems, including vestibular (balancing in space), proprioceptive (position and movement of the body), and interoceptive (internal physiological sensations from the organs) [1]. SP difficulties can affect an individual's ability to participate in daily

activities [5], such as brushing and washing hair, eating, tolerating public places, participating in sports, adapting to the environment, and properly recognizing and responding to pain [1, 3]:

“The way I experience touch can be very complex. There are things I cannot stand the touch of such as the feeling of wood, the side of paper, cement, I love to feel things that are very soft, so for example when I crochet, I have to find the softest yarn, not the scratchy stuff. I also really like sticky things such as slime or sticky fidgets. I also crave deep pressure a lot of the time. When I get these deep body inputs it helps my body relax. Often, I sleep with a weighted blanket or I use my weighted blanket when I am feeling anxious and overwhelmed.”
– Adolescent with FASD

Sensory Processing and FASD

Exposure to alcohol during the prenatal stage impacts the developing brain and body, and individuals with FASD can experience the world very differently than those without. Prenatal alcohol exposure (PAE) can directly affect an individual’s ability to process sensory information, with higher exposure leading to greater impacts [2]. However, SP differences in people with FASD have historically received less research attention than other PAE-related challenges [6]. Although sensory differences are commonly recognized in other developmental disability groups, such as those with autism, attention deficit hyperactivity disorder (ADHD), and developmental coordinator disorder, this area remains understudied in FASD [3, 5, 7, 8].

“Often my mental challenges such as anxiety can be triggered by my sensory environment... Some things that can trigger my anxiety are loud spaces, crowded big busy spaces, someone talking to me too fast or too loudly, or too many people talking at once. Another thing I have noticed is that when things like my anxiety are high, spaces that I can typically tolerate become places that I cannot tolerate.” – Adolescent with FASD

In a small number of studies, researchers have explored how children with FASD process sensory input differently from children without FASD [1-5, 7, 9]. For instance, in one recent study with more than 300 children with PAE, researchers reported that 73% of participants had clinically significant SP differences [2]. These studies have revealed differences across sensory systems, including auditory [10, 11], visual [12], and motor [13] processing, which can hinder participation in daily routines and activities [4]. Although some insight has been gained through research on SP differences in the childhood years for people with FASD, there are limited studies across the lifespan. This is an important gap considering emerging evidence for age-based trends in SP among younger children with FASD [4, 14].

Sensory needs among children with FASD are linked to important functional differences, such as challenges with adaptive skills [9, 15], externalizing behaviours [6], sleep problems [16], ADHD symptoms [10], and academic functioning [15]. Importantly, SP differences and related behaviours such as hyperactivity, distractibility, and social difficulties may have broader implications for educational, employment, health, and social outcomes for individuals with FASD [6]. With adequate understanding of the complex nature of FASD, including SP differences, it is possible to implement supportive interventions that can set a child up for success and healthier outcomes later in life [4].

“The way my sensory world impacts me can be very amazing at times and sometimes the way it impacts can be very rough. For example, sometimes when I am fidgeting it is because I am anxious or scared but then sensory things like having fidgets and keeping my hands busy also help me cope and get through those rough times.” – Adolescent with FASD

SP differences in children with FASD have also been linked to high levels of parenting stress [4, 17]. In fact, caregivers report that SP differences among young children with PAE are one of their most significant concerns. Importantly, very little is known about how these experiences change with age and how caregivers may best continue to support sensory needs for their children with FASD as they grow through adolescence and into adulthood:

*“I remember when [my daughter] was younger, I could provide her with the sensory inputs she needed, like weighted pressure, to help her regulate during escalations. However, it has become almost impossible to do that for her as a teenager, especially during her escalations, as it can become unsafe for both of us. It’s intriguing to note that despite [her] strong awareness of her sensory profile, she still struggles significantly with self-regulation.”
– Caregiver*

Two environments in which SP challenges may be especially relevant for people with FASD are medical settings and in the classroom. From a caregiver’s perspective, experiences at the hospital can be significantly impacted by sensory needs related to FASD:

“I’ve witnessed challenges with [my daughter] during our visits to the ER, especially during her mental health crises. Her sensitivity levels seem to heighten, escalating the intensity of her episodes.” – Caregiver

Whereas researchers have investigated ways of supporting sensory needs in health care settings for people with disorders such as autism, cerebral palsy, and ADHD [18-20], this area remains under-investigated for people with FASD. Similarly, there is growing evidence related to school-based sensory supports for children with autism, ADHD, intellectual disabilities, and other disorders [21, 22]. However, very little research in this area has included people with PAE/FASD. This is a critical research gap given how important the sensory environment at school can be for people with FASD:

“Even at school, I am super aware of my sensory environment all the time. Most days I take my lunch to a quiet hallway and eat there as the cafeteria is way too loud and busy. Sometimes I text my friends and invite them to join me and I just tell them I can’t do the noise... When the classroom gets too loud, I have access to another classroom that is set up in a sensory friendly way with a teacher always in there. So, if I get overwhelmed (which happens very often) I just take my books and assignments and go work in that classroom. This has been a super help for me this year.” – Adolescent with FASD

Identifying Differences and Supporting Sensory Needs

Early identification and intervention are powerful protective factors supporting healthy outcomes for people with FASD [23]. Understanding the developmental impacts of PAE on SP from an early age can greatly inform clinical response and support trajectories toward healthy outcomes [3-5]. Although evaluation of SP is not always included in FASD assessment and diagnosis, identification of SP differences can guide early intervention for people with FASD [3, 4]. Additionally, when SP is part of

the assessment process, this can help families to learn about potential roots of a child's challenges and lead to timely intervention. Given the high rates of SP differences in people with FASD, understanding the impacts of PAE on an individual's ability to process and respond to sensory stimuli is an essential step in identifying needs and supporting individuals with FASD throughout the life course [3, 6].

"I have done a lot of exploring about how my sensory world impacts me and slowly every day I am finding more answers all the time!" – Adolescent with FASD

Emerging research on sensory-related interventions for individuals with FASD is promising. Pilot research has indicated that virtual sensorimotor training may help children with FASD to improve their sensory adaptation, motor performance, and balance [24, 25]. Multi-sensory "Snoezelen" rooms have been used to support children with FASD in the context of mental health therapy [26], and adolescents with FASD have reported that sensory strategies, such as colouring, listening to music, sensory fidgets, and exercise to be useful in helping with self-regulation and coping [27, 28]. From a caregiver's perspective, simple accommodations to account for SP differences can have great impacts on daily functioning:

"My youngest son was unable to focus on working rather than socializing in the busy classroom. He became great "friends" with the principal at his school. The teachers recognized his sensory challenges and encouraged him to go to the principal's office to do his classwork in a quiet, yet supervised space. A simple yet effective accommodation." – Caregiver

Researchers and parents alike emphasize the importance of explicitly asking individuals with FASD and their caregivers about their concerns related to SP, which allows for earlier identification and more effective responding [4]. These conversations provide opportunities for individuals with living experience to identify strengths and share concerns and insights that inform care planning [4]. As with all intervention, a one-size-fits-all approach is unlikely to universally support the sensory needs of all people with FASD, and an individualized approach is recommended [29]. Interventions that center on individual differences and needs, including SP challenges, while incorporating contextual and environmental factors that build on individual strengths and resources, can help to shift trajectories and promote healthy outcomes [4].

"One thing that my mom has always taught me is that I don't always have to be the one to change to fit into the world, the world can change to fit me too... If I do get overwhelmed, can you help me find a space to cool down, put me in a quiet safe space... Most importantly – please understand that 99% of the time I am doing the best that I can." – Adolescent with FASD

Conclusion

Sensory processing differences can have significant impacts on daily life for people with FASD, their families, and wider support systems. With early identification, intervention, and supportive services, improvements and healthy outcomes are possible. It is important to consider SP differences when assessing needs of individuals FASD to understand behaviour and needs, inform intervention, and support optimal outcomes. Awareness and recognition of SP differences and their subsequent impacts on behaviour can provide a framework to understand some of the challenges experienced by individuals with FASD and their families, and to promote successful trajectories and wellbeing.

Recommendations

Research Gaps

- More research is needed on the prevalence and impacts of SP differences among people with FASD across the lifespan. Examination of developmental trajectories and impacts of SP beyond childhood will inform the development and implementation of early interventions and supportive services for individuals with FASD.
- Additional studies are needed to examine environmental and contextual factors that may influence SP and associated functional challenges among people with FASD.
- More research specific to SP interventions for people with FASD is needed, such as implementing positive behavioural supports and adapting individual environments.
- Given the overlap in symptomology and sensory needs associated with different neurodevelopmental disabilities, more research is needed to disentangle co-occurring symptoms and further explore the brain-behaviour relationships associated with PAE.
- Neuroimaging techniques, including MRI and MEG, may provide insight into brain-behaviour connections related to SP and assist with the identification and implementation of intervention and supportive services for people with FASD.
- More research is needed to examine the use of SP assessment tools with people with FASD. Exploring ways in which traditional measures may be adapted, modified, and normed for better use with this population will be important.
- Future research should include individuals, families, and service providers to incorporate lived experiences regarding SP differences in FASD. All interest-holders should be included as research partners to ensure studies hold value, meaning, and real-world applicability. Understanding how people with FASD and their families manage, navigate, and cope with activities and environments based on their SP patterns can help inform the development of effective interventions.

Practice and Policy Considerations

- SP is an important area for consideration during routine screening, clinical evaluations, and other assessments. Explicitly asking individuals and caregivers about their SP experiences may aid in the earlier identification of and support for concerns that may arise from SP differences. Early intervention can help mitigate the impacts of SP differences and adverse experiences associated with these challenges for people with FASD.
- Assessment for sensory needs during FASD diagnostic testing can be critically helpful to inform intervention planning and support healthy outcomes.
- To ensure a balanced understanding of SP needs, consider both the individual's challenges *and* their inherent strengths and abilities. Individualized strength-based approaches can help to promote healthy outcomes and reduce the stigma surrounding FASD.
- Holistic context-focused approaches to developing SP skills, modifying the environment, and optimizing developmental outcomes and trajectories for individuals with FASD may be especially promising. Service providers can support individuals with FASD by adapting their environment and educating other professionals on how SP differences may impact behaviour across settings.
- Service providers and policy makers should consider caregiver perspectives and needs related to SP to enhance the development of family-centered interventions, strengthen parent-child

connectedness, and foster effective relationships between practitioners and families impacted by PAE and FASD.

Professional Training

- Maintaining a thorough understanding of FASD can help service providers to assist families seeking appropriate information or support. Educational and training initiatives about FASD as a whole-body disorder are important for frontline professionals to confidently recommend and implement appropriate interventions and supports for individuals with FASD and SP differences.
- Post-secondary training and curricula for health professionals and other service providers who support those with sensory processing needs and disorders should include information about FASD. Embedded in training, this education can help stimulate understanding and further research.
- To enhance awareness and professional competence, training for educators, health care professionals, and any other service providers supporting those with FASD should include sensory awareness training and information about SP differences associated with neurodevelopmental disabilities.

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