

### NOTHING ABOUT US WITHOUT US: ESSENTIAL CONSIDERATIONS FOR COLLABORATIVE FASD RESEARCH

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#### ABSTRACT

##### Background and objective

Historically, Fetal Alcohol Spectrum Disorder (FASD) research has been conducted on individuals with lived experience rather than with them. This article draws on feedback from workshops with individuals with lived experience, in which a collaborative approach was followed, drawing on patient-oriented and participatory action research methods. We provide an overview of the feedback, including barriers to participation alongside strategies to address these barriers, facilitating meaningful involvement in the research process. The writing team includes those with lived experience and research backgrounds. In addition, we make a distinction between the experience of those with FASD (what is called “in-body lived experience”) and those that have caregiver experience (what is called “in-home lived experience”). By lowering barriers, the goal is to bring in the many different perspectives of those with lived experience.

##### Material and methods

A keynote presentation and two workshops were held in 2018 at an international FASD conference bringing together individuals, families, agencies, and researchers. Participants were asked what they required to participate in FASD research more thoroughly. The goal was to understand barriers to participating in FASD research. In the first workshop (n=65), imagined for general conference participants including caregivers, service providers, policymakers, and researchers but primarily attended by caregivers and service providers, participants were asked to rank barriers through a “dotmocracy” process. Dotmocracy (or dot-voting) is a collaborative prioritization technique commonly used in group facilitation. A tally of the number of dots assigned to each barrier by participants was used to rank the importance of the barriers identified. Small groups discussed strategies to address the top 10 barriers. In the second workshop, composed of adolescents and adults with FASD (n=60), the participants were asked to share the obstacles they faced in research as a collaborator or as a research participant and their suggestions for future research area priorities.

## Results

Participants in the first workshop noted core concerns, including the need for financial support, barriers to informed participation, unconscious bias of researchers, lack of a common language, lack of time and support to participate, absence of shared leadership in the research, perceived absence of benefits for participants, lack of accommodation for the unique needs of individuals with lived experience, scarcity of resources to accommodate those needs and insufficient communication on current FASD research projects. The information from individuals with FASD was similar and focused on the unique needs and barriers to fully participating in FASD research either as a collaborator or research participant. For example, participants identified the need for researchers to accommodate language comprehension differences, memory issues, anxiety, and sensory issues experienced by individuals with FASD. In addition, they identified barriers to participation such as finances, lack of transportation, insecure housing, and childcare demands. Finally, participants noted that FASD is a spectrum disorder and people on all ends of the spectrum need to have a voice.

## Discussion

The workshops provided a wealth of information regarding research areas on which to focus, unique needs and barriers to participation, and their need to have a voice. Research that is attentive to each of these groups' unique needs will allow for the inclusion of the widest group of individuals that identify as having lived experience relative to FASD. As a result, patient-oriented and participatory action research can be better represented in the field of FASD.

*Keywords:* Fetal Alcohol Spectrum Disorder; advocacy; participatory action research; patient-oriented research; disability justice; research ethics; lived experience

## INTRODUCTION

The authors of this article argue that the predominant trends in Fetal Alcohol Spectrum Disorder (FASD) research do not engage individuals with lived experience. There is both capacity and an ethical need for more research collaboration that includes individuals and families with lived experience. It is most common for research to be conducted *on* individuals and their caregivers rather than *with* those with lived experience.

Patient-oriented and participatory action research methods outline practices to create collaborative research projects. One of the main principles of patient-oriented research is that the research is directly focused on a patient and how a disease or condition impacts them.<sup>1</sup> Participatory action research is unique in that it builds in a space for reflection alongside data collection, and in health-based research, the intention is to improve health and reduce health inequalities.<sup>2</sup> More specifically, participatory action research underscores the

importance of collaboration and consultation *before* research starts. This space, this pause, allows the group to take stock of challenges and collectively get everyone to the table. FASD research has significant challenges bringing people to the table, such as financial and communication barriers.

Disability Justice frameworks focus on intersectionality and collective access and liberation, with leadership coming from those most impacted.<sup>3</sup> So, by extension, a Disability Justice approach to research would necessarily expect research projects to be driven by those with lived experience, but how to bring that about? The current challenge to FASD research is that there is capacity and interest for individuals with lived experience to contribute to research, but there has not been a general uptake or support of that interest. Concurrently researchers may not have seen how or why to bridge lived experience and research design.

This was the challenge presented to the authors of this paper at the beginning of their collaboration.

The collaboration brought together individuals with lived experience and researchers who wanted to foster robust and ethical collaborations to inform current and future research projects. The collaborative team includes an individual with FASD (NS), 2 caregivers of individuals with FASD (DR and LB), and 2 FASD researchers (MS and RP). – the social location of each author is unique. Social location refers to the “particular constellation of intersecting social identities” that an individual holds.<sup>4</sup> Social location is understood to be unique for each individual and can be a mixture of race, class, physical size, (dis)ability, gender, sexuality, age, geographic location, and all other key characteristics that shape one’s daily life. Often thought of within the framework of intersectionality<sup>5</sup> social location outlines a theory of self and identity formed through interlocking experiences of subjugation and privilege.<sup>1</sup> Crenshaw argues that we need to understand how different elements of our lived experiences intersect.<sup>5</sup> For example, when we look at our experiences in life, we can isolate characteristics. The single experience of being Black or being a woman does not capture the total experience of being Black and a woman. Intersectionality allows for a more nuanced way to think about experiences of privilege and subjugation by thinking about how our different social locations intersect with one another.

In this way, social location and intersectionality can help us better understand the role of lived experiences and how it shapes our understanding of our own lives and the lives of those around us. This, in turn, can shape how we understand the world around us. Taken together, the authors represent 120+ years of expertise developed through lived experience and research in FASD.

This article examines two workshops held with individuals with lived experience and shares their insights on what they need to engage in research,

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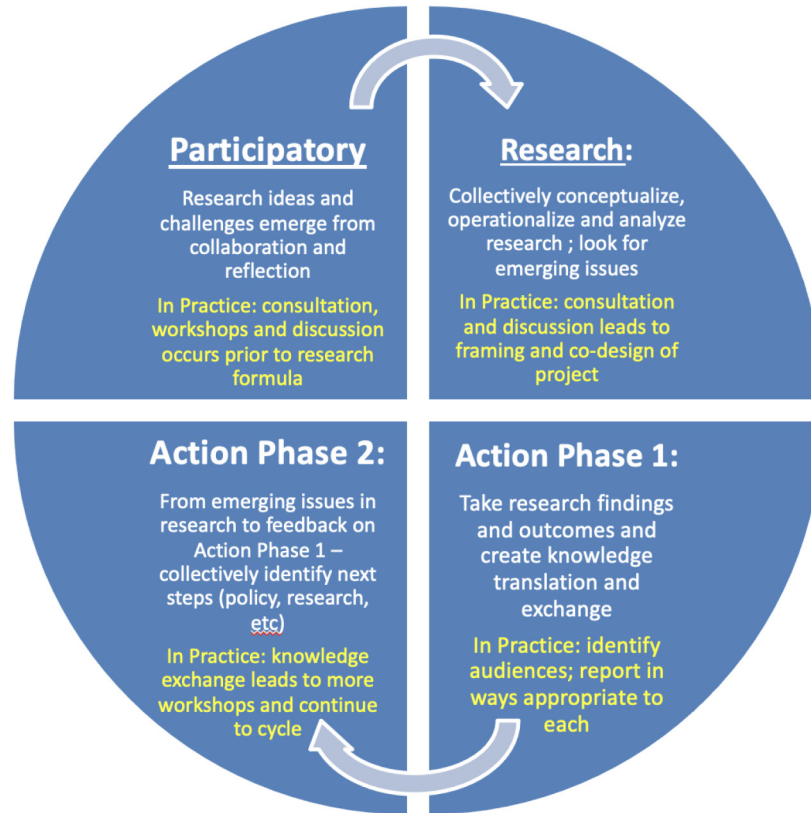
<sup>1</sup> For a helpful resource that discusses social location and its complexity review the following free resource: “Understanding Social Locations & Identities Part 1 with Dee Watts-Jones, <https://www.youtube.com/watch?v=pSj5xCO8eBo>; “Understanding Social Locations & Identities Part 2 with Dee Watts-Jones,” <https://www.youtube.com/watch?v=eO-8Q21HGjio>; “Social Locations & How They Impact us Part 3 with Dee Watts-Jones,” <https://www.youtube.com/watch?v=T-h0gnJes0M>

barriers to study, and areas of research interest. As this was an information-gathering process rather than a research project, ethics approval was not sought. However, consent to participate was implied by attendance. Research in the field informs evidence-based practices, and as such, the goal is to transform the field of FASD research, supports, and services through collaborations that draw on the collective expertise of researchers *and* those with lived experience.

Those engaged in participatory or patient-oriented research will find this article of particular interest as it offers discussion and strategies for meaningful collaboration - from research design and funding to ethics board applications, data collection, analysis, and knowledge translation. Figure 1 illustrates the participatory research process and the outcomes of the various stages. This process was followed in developing the keynote address and workshops and analyzing the sessions presented in this article.

## WHY PARTICIPATORY RESEARCH IS NEEDED

Research in the field is vast. A *general* search of academic work on FASD results in about 13,600 pieces (google scholar search). An examination of more recent academic work (2011–2021) finds 10,300 academic articles published about FASD in the past 10 years (google scholar search). However, when one drills down to consider collaborative or participatory projects, the numbers narrow radically. For example, if one looks for articles about FASD and participatory research, we find only 227 articles.<sup>6,7</sup> Similarly, when one looks for pieces that discuss patient-oriented research, we find 24 articles. Taken together, we can see that there are approximately 251 articles that represent two of the many participatory methods available. Of course, the field narrows as expected because these are specialized methodologies. However, if one looks at the field of autism spectrum disorder, the same phenomena is not true as there are 1,180 academic resources available that discuss participatory action



**FIGURE 1** Participatory research diagram.

research and 121 that discuss patient-oriented research (Google Scholar search). This inventory of the academic pieces available via a cursory Google Scholar search offers a general overview. It is not a comprehensive literature review or scoping document but rather a snapshot.

We understand FASD to be a complex and life-long disability.<sup>8</sup> It is also a disability that draws together a multidisciplinary research field including health,<sup>9,10</sup> justice,<sup>11,12</sup> and education.<sup>13,14</sup> There have been significant contributions to the field over the past four decades. There are critical examples of high-impact participatory research completed in the field.<sup>15</sup> However, most of the research in the field is developed by individuals and teams that do not work collaboratively with individuals with lived experience. This has created a methodological quandary: why is FASD research so out of step with

participatory research in disability studies? As Sample<sup>16</sup> argues “the use of the PAR [Participatory Action Research] approach in studies related to people with disabilities is not only a necessary direction for research but an ethical one.” The absence of this approach serves to dismiss and negate the central role and importance of lived experience.<sup>17</sup> In other words, research on disabilities that excludes lived experience can further marginalize already marginalized individuals and groups.

There can be several reasons for this “exclusion” in research methods and practice. For example, some have argued that more inclusive methods committed to equity and/or anti-colonial or anti-racist practices can have hurdles in having that work recognized in academia.<sup>18,19</sup> These barriers within academia including challenges making it past peer review<sup>20</sup>, then hinders the possibility of the research

finding an audience. In addition, a range of other issues can arise, including ethical issues with the method,<sup>21</sup> which can lead to methodological blinders that limit the capacity for researchers to see the “value” of lived experience in particular research projects.

However, these misconceptions or presumptions about methodological “fit” have been countered by a range of participatory projects used across disciplinary fields that demonstrate the role it has in “advancing scientific knowledge as well as for solving practical problems”<sup>22</sup> including application in policy work.<sup>23</sup> There has been clear notation on how academic rigor can surround the method<sup>24</sup> and demonstrations in which the reported commitment to participatory research can fall flat.<sup>25</sup> At the same time, participatory research can serve as a type of “disruptor” to generate new, unexpected, and inter-sectional knowledge.<sup>26,27</sup>

Many have paved the way to demonstrate the role of PAR as an innovative methodological approach and one that is bound up in broader equity considerations. Many projects have mobilized a participatory approach to research in part because “social action built into the project processes improves opportunities for knowledge transfer.”<sup>28</sup> Accordingly, it is important to expand and broaden the scope of services and supports that are available to assist individuals – and to do so, it is critical to bring in the widest range of lived experiences and the complexities of those lived experiences to create new collaborations and potential for knowledge generation. To help facilitate these types of collaborations, we decided to speak to different audiences to share ideas and get feedback.

## METHODS

This article disseminates the findings from two workshops held at an international FASD conference in 2018. The workshops were held to solicit feedback regarding barriers to participation in research and developing processes to address these

barriers. These strategies can facilitate meaningful participation from individuals with lived experiences at all steps in the research process.

### *The Workshops*

We held one keynote session and two workshops at an international FASD conference in 2018. This annual conference brings together individuals, families, agencies, and researchers. The keynote panel represented the strategy we were promoting that collaboration with all those involved in FASD is essential, so our panel included an individual with FASD, caregivers, and researchers in the field of FASD. In presenting the keynote, we also addressed a central challenge at academic conferences: the competition for time and attention. While this conference created two streams for participants – one for those with FASD and another for researchers, workers, and caregivers – the reality is that the pace of the scheduling of an academic conference finds a reliance on concurrent panels, which means each panel competes against others for attention. In this sense, the keynote was when everyone might be in one room.

Two workshops were held following the keynote session – one workshop was for the general conference participants and one for the adolescents and adults with FASD attending the conference. In these workshops, participants were asked what they required to fully participate in FASD research. The goal was to discuss with researchers and caregivers about practical ways of conducting collaborative research from the initial phase of the research question development to the final phase of knowledge translation.

The first 1.5-hour workshop was advertised in the conference brochure as open to all conference participants. It was one of seven concurrent sessions at the conference. Approximately 65 people attended the workshop. Descriptive information of the participants, such as age and gender, was not formally collected and therefore is not described here. Through a show of hands, all but one individual identified

themselves as caregivers of individuals with FASD and FASD frontline service providers. Only one individual identified as a researcher. Participants in the workshop were not offered any specific incentive to participate. The workshop was facilitated by the authors of this article. Participants were divided into small groups and asked to discuss their positive and negative experiences in participating in FASD research, either as a collaborator or as a participant in a research project. They were then asked to identify barriers to conducting truly “patient-oriented research.” Each group nominated a spokesperson to present the group’s list to all workshop participants. The workshop facilitators recorded the barriers on flip chart paper and then posted them on the walls. Once these lists were posted, a “dotmocracy” process was used to rank the importance of the barriers.<sup>29</sup> Each workshop participant was given a certain number of stickers they could use to indicate which barriers they felt were the most important. The total number of stickers for each barrier was tallied, and the top 10 barriers were identified. The workshop participants then rejoined their small groups to identify solutions to the top-ranked barriers. See Table 1 for the list of barriers and solutions generated.

The second workshop was conducted the following day and was limited to the adults and adolescents with FASD attending the conference. Approximately 60 individuals attended this 1-hour session. We had two goals for this workshop. The first was to validate the information we received on barriers to collaborating or participating in FASD research and identify strategies for addressing those barriers. The second purpose was to identify priorities for FASD research from the perspective of individuals with FASD so that we could provide that information to those doing FASD research through various mechanisms. This was done in a large group discussion format facilitated by an adult with FASD (NS), two caregivers (LB and DR), and with an FASD service provider/researcher (RP) recording all responses. The responses were compiled following the workshop.

This process allowed us to begin developing tools for researchers and individuals to assist them in preparing to be a collaborator in FASD research.

## RESULTS

### *Workshop 1 Results*

In the first workshop, participants identified the following areas in which caregivers and individuals could be involved in the research process: pre-research consultation; research design; grant writing; recruitment; data collection; data analysis; synthesis of key findings; knowledge mobilization and translation; and outreach including policy development, practice change, and further research or next steps.

The participants identified barriers that may prevent caregivers and individuals with FASD from collaborating on or participating in FASD research. One theme addressed the participants’ perception of barriers associated with the characteristics of the research/researcher. These included: the unconscious bias of the researcher; insufficient investment in the FASD community; absence of community-initiated research designs; insufficient community coordination; lack of outreach and strategies to engage individuals with lived experience in FASD research; insufficient accommodation for the unique needs of those with lived experience; absence of a common language; and a deficit-focused perspective of research rather than a strength-based focus. We will later discuss the underlying relationship to ableism that ties many of these elements together.

Participants acknowledged the challenges researchers face, which may be due to the stigma associated with FASD. These challenges include the difficulty of obtaining sustainable FASD research funding, impacting the ability to provide in-depth, longitudinal research. In addition, developing long-term relationships was seen as important but difficult without sustainable research funding. Limited resources and/or bureaucracy were also identified, affecting funding applications and/or ethics approval.

Issues related to the relationship between researchers and individuals with lived experience

were identified, including the absence of shared or inclusive leadership in research; ineffective communication; limited cultural connection with those with lived experience; challenges associated with geography; lack of trauma-informed approaches; and researchers unengaged with the community. In addition, participants identified the need to develop research knowledge and skills in people with lived experience.

Characteristics of individuals with lived experience were also identified as barriers to collaborative FASD research. These included: limited access to researchers and/or clinicians; insufficient emotional support for individuals with lived experience both during and following research participation; lack of empowering individuals with lived experience; feelings of inferiority and/or lack of confidence on the part of those with lived experience; absence of perceived benefits for participation including, insufficient financial supports; conflicting demands on time and energy; and a lack of knowledge of projects and knowledge of research process. In addition, the caregivers participating in the workshop noted that an absence of respite services was a significant barrier to inclusion due to insufficient financial support.

The barriers that were prioritized by participants and the solutions suggested for overcoming those barriers are presented in Table 1.

### ***Workshop 2 results***

The first theme identified was characteristics of the research and/or researcher and included: lack of funding for transportation; reimbursement of expenses; childcare; and reimbursement of time to participate in the research. Individuals with FASD also identified the lack of understanding of the complexity of FASD and the unique presentations of individuals with FASD. As a result, the specific accommodations needed for individuals with FASD to participate do not occur and/or there are unrealistic expectations. This will be further explored in the discussion related to the role of ableism in research.

The relationship between the researcher and individuals with lived experience was the second

theme identified. This theme included not being seen as a whole person or an equal in the research process. This perceived lack of respect was a powerful message provided by the adults and adolescents attending the workshop. They had experienced being talked down to or treated like a child when participating in FASD research. They also noted that they had experienced little follow-up or individual feedback on research results. Communication or sharing a common language was identified as barriers to developing effective collaborative relationships.

The participants also identified individual characteristics which may present barriers to full participation. These included: the difficulties they experienced in self-advocacy; the need for support persons during the research, anxiety and sensory issues; and getting lost and confused, particularly with the language demands.

They provided powerful messages to researchers that there needs to be representation from people at various places on the spectrum in FASD research and that “scientific talk” was a significant barrier that essentially excluded them from active involvement in collaborative research. The strong take-home message they wanted us to leave with was that researchers need to get to know the person and not the disability. The results of the second workshop are summarized in Table 2.

People with FASD were also interested in seeing many areas of research completed, including how to simplify assessment and diagnosis, the kinds of everyday supports that can make life easier, getting a better understanding of their sensory, communication, and learning needs, and recommendations for independent living, employment, budgeting, and parenting. Again, the knowledge and wisdom of the group of adults and adolescents was profound. The results of their recommendations for research priorities are summarized in Table 3.

## **DISCUSSION**

As noted previously, research in the field of FASD is vast. There is a lot of important research

**TABLE 1** Caregiver Barriers.

<b>Top Ten Barriers (rated from #1 priority down)</b>	<b>Barriers</b>	<b>Solutions</b>
<b>1. Financial Supports</b>	a) Participants need financial supports: might include transportation, respite, honoraria, meals, translator	a) Grants b) Government funds for Indigenous Communities c) Community Based Fundraising
<b>2. Informed Participation</b>	a) No checklist to vet approval is available for caregivers or people with FASD b) Prospective participants do not know who is doing research or what the research is about	a) Find Common (Plain) Language b) Involve Experts in community participation c) Include more voices – community collective wisdom
<b>3. Unconscious Bias</b>	a) Current research does not recognize strengths – focused on deficits b) Leading questions that pigeonhole	a) Educate and make the unconscious conscious b) Build awareness
<b>4. Common Language</b>	a) Current knowledge translation does not meet the needs of all parties b) Lack of plain language	a) Get a few people from the group/ community to test the language and review questions beforehand
<b>5. Time/Support</b>	a) On-line availability of support b) No time to be involved in research – family commitments are too great. c) No money to travel or pay for respite. Even if there was, there are no providers who work well with the children. d) Families worry about their children when they are gone: will the caregiver provide the needed support? e) Presently there is not the flexibility to build and maintain connections with varied people: family, people with FASD, service providers, researchers	a) Funding b) Support c) Education online availability
<b>6. Shared Leadership</b>	a) Partnerships/ shared leadership	a) Take the time to develop trusting relationships.
<b>7. Benefits</b>	a) Are the benefits of participation worth it; will the outcome mean more services.	a) Let people know what the benefits are prior to attending. b) Let people know what the goals of the research are – what is it going to do?
<b>8. Unique Needs</b>	a) Lack of opportunity in smaller communities - need to bring the research out to them! b) Rural; Indigenous populations are not understood. Researchers do not realize this and are not listening to needs	a) Researchers need to be aware that not all areas have sufficient internet services for online surveys. Options should be available in printed form. b) Cultural awareness and sensitivity are essential



**TABLE 1** Continued.

<b>Top Ten Barriers (rated from #1 priority down)</b>	<b>Barriers</b>	<b>Solutions</b>
<b>9. Resources/Ethics</b>	<ul style="list-style-type: none"> <li>a) Limited resources around design, inclusion, time, bringing people together.</li> <li>b) Regulations and bureaucracy</li> </ul>	<ul style="list-style-type: none"> <li>a) Build a similar template for ethics for use by all researchers at all universities.</li> <li>b) Ethics approval should include the community ethically approving of the research</li> </ul>
<b>10. Where are the Projects?</b>	<ul style="list-style-type: none"> <li>a) Where can one go to find the research projects?</li> <li>b) There is a lack of understanding of how to access research.</li> </ul>	<ul style="list-style-type: none"> <li>a) A central online resource listing of current research projects.</li> </ul>

**TABLE 2** Barriers for Individuals with FASD.

<b>Top Barriers</b>	<b>Detailed explanation</b>	<b>Solutions</b>
<b>1. Transportation</b>	<ul style="list-style-type: none"> <li>a) Can't take mass transit alone.</li> </ul>	Provide transportation for the participant and support person.
<b>2. Communication</b>	<ul style="list-style-type: none"> <li>a) Being misunderstood</li> <li>b) Not being able to get my view across.</li> <li>c) People not listening.</li> <li>d) Language barriers.</li> <li>e) Blanket statements don't work.</li> <li>f) Discount my disability because I can talk well.</li> </ul>	Use people with FASD as knowledge translators. Use support persons or others as "translators", to make sure researcher and participant understand each other. Develop awareness of individual strengths and challenges
<b>3. Getting Confused</b>	<ul style="list-style-type: none"> <li>a) Need to show, not tell.</li> <li>b) Be aware of the kinds of questions and the way questions are asked of people with FASD.</li> </ul>	Use visual cues. Show me what to do.
<b>4. Anxiety</b>	<ul style="list-style-type: none"> <li>a) Around transportation needs.</li> <li>b) Meeting and being with new people.</li> <li>c) The speed at which the researcher is asking questions.</li> </ul>	Provide transportation and/or detailed instruction for individual and support person. Acknowledge that meeting new people is anxiety provoking and take time for introductions. Take extra time for participant to feel comfortable. Set up the environment as a relaxing setting: quiet, ambient lighting, comfortable seating
<b>5. Sensory Issues</b>	<ul style="list-style-type: none"> <li>a) The physical environment</li> <li>b) Lighting</li> <li>c) Temperature</li> <li>d) Sound</li> </ul>	Ask about sensory issues before meeting with the participant, set up environment accordingly.

**TABLE 2** Continued.

<b>Top Barriers</b>	<b>Detailed explanation</b>	<b>Solutions</b>
<b>6. Money and reimbursement of expenses</b>	<ul style="list-style-type: none"> <li>a) For time</li> <li>b) To cover expenses</li> <li>c) Accommodation</li> <li>d) Transportation</li> <li>e) Companion</li> <li>f) Child care</li> </ul>	Funding and ethics approval need to recognize participants' needs so that they can comfortably be part of research.
<b>7. Accommodations not provided</b>	<ul style="list-style-type: none"> <li>a) Use of language by researchers</li> <li>b) Proper seating</li> <li>c) Breaks</li> <li>d) Accommodation for sensory/ environmental needs</li> <li>e) Availability of a "translator" or support person to assist in understanding</li> </ul>	Use common language. Avoid the use of anachronisms and jargon. Address sensory issues. Provide accommodations such as the presence of a support person or translator.
<b>8. Family problems that don't allow me to participate or make me withdraw</b>	<ul style="list-style-type: none"> <li>a) Lack of accommodation for responsibilities of the individual</li> </ul>	Researchers need to be flexible regarding appointments and locations.
<b>9. Lack of support</b>	<ul style="list-style-type: none"> <li>a) No family</li> <li>b) No support system</li> <li>c) No support person provided</li> </ul>	Identify what the individual's support needs are and strategize with the individual opportunities to provide support to participate.
<b>10. Time</b>	<ul style="list-style-type: none"> <li>a) Working and projects do not accommodate my schedule</li> </ul>	Researcher's need to be flexible and respect participants' schedules.
<b>11. Being disconnected</b>	<ul style="list-style-type: none"> <li>a) Beyond tokenism</li> <li>b) Not being treated as an equal</li> </ul>	Full involvement of individuals with FASD in all stages of FASD research.
<b>12. Not being seen as a whole person with strengths as well as limitations</b>	<ul style="list-style-type: none"> <li>a) No acknowledgement of wisdom and knowledge of people with FASD</li> </ul>	Listen to individuals with FASD as they describe their experience and what they have learned. Respectful communication.
<b>13. Unrealistic expectations</b>	<ul style="list-style-type: none"> <li>a) We are seen as people who can do everything or nothing.</li> </ul>	Recognize that FASD is truly a spectrum disorder and each individual has both strengths and challenges. Each individual with FASD is unique in their strengths and challenges.
<b>14. Research that focuses on groups rather than individuals</b>	<ul style="list-style-type: none"> <li>a) We are not all the same.</li> </ul>	Provision of specific research results pertinent to the individual.
<b>15. Lack of respect</b>	<ul style="list-style-type: none"> <li>a) People see us as children.</li> <li>b) Not being included.</li> <li>c) Being talked down to.</li> </ul>	People with FASD have many strengths. Recognize and respect those strengths while accommodating their challenges. Include individuals with FASD in all aspects of research not just as participants or informants.

**TABLE 2** Continued.

<b>Top Barriers</b>	<b>Detailed explanation</b>	<b>Solutions</b>
<b>16. Lack of accommodation to the needs of people with FASD</b>	a) Make it interesting/fun for us. b) Needs to be a perceived benefit to participants.	Help connect the individual with FASD with the research and how it may help change theirs and others' lives.
<b>17. Need to have representation from people at a variety of places on the spectrum</b>	a) There needs to be a voice for those at the more severe end of the spectrum.	Recognize FASD as a whole- body spectrum disorder.

**TABLE 3** Research Priorities Identified by Individuals with FASD.

1. Genetic testing for people with suspected prenatal alcohol exposure including strategies that can bypass birth mother admission.
2. FASD DNA ancestry.
3. Medical history.
4. More outcome research – finding out what works.
5. More research directed by individuals with FASD.
6. More research based on individuals rather than groups including case studies, longitudinal follow-up and research that looks at FASD from the individual’s point of view.
7. Sensory overload - why does sensory overload occur more often in people with FASD and what can you do about it?
8. Effective information for employers on accommodating for processing speed.
9. Skills for employers in accommodating workers with FASD.
10. Effectiveness of supports for people with FASD, especially looking at funding models.
11. Effective fundraising strategies.
12. Effective communication strategies for people with FASD.
13. Effectiveness of job coach programs, such as job coaches staying with the individual.
14. Importance of services over the lifespan.
15. Effectiveness of medication for FASD and other conditions common for people with FASD.
16. Is there an FASD profile? Could that include pinpointing indicators for FASD, should there be any.
17. Survey for doctors on their knowledge of FASD.
18. Strategies for self-advocacy.
19. What does aging with FASD look like?
20. Does FASD increase the likelihood of early dementia?
21. The use of people with FASD as knowledge translators.
22. Misdiagnosis in FASD.
23. Knowledge of FASD in the education system – what works and effective learning strategies.
25. Knowledge of FASD with the police – effective strategies for educating the police on FASD including tools for police such as info sheets on FASD that individuals with FASD could provide officers.
26. What works in addictions treatment for people with FASD, for example asking if day passes during residential treatment affect people with FASD, and whether there are more sustainable approaches and supports in addiction recovery.
27. Research on the inconsistency of FASD, some days you can do things, and other days you can’t, and availability of more sustained supports.

being undertaken, but there is also a limited amount of research driven by the perspectives of those with disability. This is a critical absence, one that was raised by participants and one that impacts the types of research that can be undertaken, which then impacts our capacity to understand the disability in all its complexities, which in turn effects evidence-based programs and policies. Workshop participants noted frustration with this, as policies developed from research findings continue to miss important details of their lives, and therefore policies to address these are overlooked.

There can be many reasons why there is limited engagement with participatory methods, and it is essential to note. One significant challenge can be ableism in academic institutions<sup>30</sup> that do not understand the complexity and capacity of those with complex disabilities to be involved in research.<sup>20</sup> Researchers and projects can experience institutional hesitation when seeking to conduct research or work with individuals with cognitive disabilities. This hesitation can become apparent when there are challenges in getting permission to conduct research. This hesitation – which can directly hinder permission to conduct research – is informed by numerous examples of research conducted *upon* vulnerable individuals, including those with intellectual disabilities. In the medical, behavioural, and social science fields of research, unethical research practices have victimized individuals in the name of academic or scientific knowledge.<sup>31</sup> The Nuremberg Code serves as a stark reminder as it was explicitly created in the wake of Nazi experimentations and affirmed that each individual must give voluntary consent to any experiment on their body.

Given that these institutional barriers are complex, they are at once informed by unethical histories in which individuals with disabilities were victimized in the practice of research which now produces challenges when researchers come forward with research proposals that identify a project focused on the vulnerable (which includes children, prisoners, and those with disabilities) persons. However, we can directly intervene to remind

academic institutions that “vulnerable” does not mean incapable. In research ethics applications and in our research design, we can draw upon: the findings from the workshops, where participants advocated for involvement in research and their desire to participate in research design and, indeed, all phases of the research process; the collective insights of the 251 articles that describe participatory projects; and funding agencies that place emphasis on research that is accessible. All the above can assist researchers in thinking about barriers and strategies that can facilitate collaboration.

The feedback received in the workshops pointed to the role of ableism in project development, methodological design, data collection, and analysis. Individuals were remarking that they were not invited to participate in robust and fulfilling ways. And for those that might be invited to participate, their participation was limited and/or they reported that their needs were not accommodated to allow for their full participation. Normative understandings of capacity and ability infiltrated research spaces, which undermined the overall potential to do research *together* in new and exciting ways. Whose time mattered and how time was valued also impacted how research was conducted and how people’s participation was supported and compensated. Participants did not feel that their involvement in research had been supported in meaningful ways. As such, research striving for inclusion was still falling short by creating a normative understanding of what participation is by using flawed and ableist assumptions.

The absence of a participatory approach can be perceived by individuals with lived experience as dismissing their knowledge and expertise. It also affects the ability to partner and collaborate and can be perceived as further stigmatizing an already stigmatized group of people. It can also limit the effectiveness of the research in bettering the lives of those living with FASD.

Returning to the two workshops, each provided a wealth of information about doing better when engaging in collaborative research with individuals

with lived experience. The workshops also allowed exploring the nuance and complexity of what we mean when speaking about lived experience—to explore what a caregiver would need relative to what someone with FASD might need to be supported in research. Very few participants in either workshop had participated in collaborative research but expressed a strong desire to be a collaborator. That desire must be met with researchers and research teams that are FASD-informed and understand the unique needs of participants with in-body and in-home lived experience. If research projects could be structured to welcome and support each of these unique perspectives, we would be in an excellent position to press into new research areas.

Unfortunately, the opportunity to create a dialogue between people with lived experience and researchers did not occur as there was a visible absence of researchers in the audience. Even though the workshop entitled “Nothing About Us Without Us: What do Families and Individuals need to participate Meaningfully in Research?” was promoted to all conference participants in the conference brochure and was verbally promoted during the keynote presentation, only one researcher attended the workshop. The workshop was one of 7 concurrent sessions. At the keynote, those with in-body lived experience sat at tables with researchers, clinicians, frontline workers, policymakers, and those with in-home lived experience. The whole field of FASD sits in the audience. We were hopeful that the first workshop would reflect the diversity of those who could and should be involved in collaborative FASD research.

The lack of insights from researchers is a study limitation that needs further exploration. But profoundly, this was a missed opportunity for researchers to hear directly from families and caregivers about the impact of research and perhaps develop new skills and strategies to enhance FASD research.

Following the workshops, the research team developed two tools for helping individuals with FASD understand the expectations and what they could ask for when participating in FASD research,

either as a participant or a collaborator in developing the research. These tools will be reviewed with groups of individuals with lived in-body and in-home lived experiences before publication and distribution.

### ***Strategies to address key barriers***

Based on the authors’ experience and the data gained from individuals with lived experience through the workshops, we propose the following strategies for researchers to address these barriers.

- Difficulty providing payment for time, funding for transportation needs, childcare, etc.
- Collaboration on teams can be stalled, and frustrations mount when the issue of compensation arises. One strategy is for researchers to work with the research ethics boards before community engagement to identify limitations and then collaborate with the office on the role of the collaboration (A review of institutional protocols alongside a review of compensation options requires the willingness and capacity to treat those with lived experience as experts/consultants. For example, it might mean that those who later engage in interviews need to be supported to participate by more than a small gift card.
- Having a support person attend (including funding)
  - Similarly, for some individuals to attend, one must account for the time and availability of both the individual and someone in their broader circle of support. But, again, there are ways to attend to this through early collaboration with your team and the research office – for example, is mileage compensation helpful? If yes, how can mileage be compensated in ways that work for the institution.
- There is difficulty with asking specific questions from caregivers about their loved ones as they are treated as secondary participants, and consent is required.
  - This is a clear opportunity to explore the complexity of lived experience. If the team

asks those with in-home lived experience to speak to their own experiences in being a caregiver, then the data is grounded in the lived experience of that individual. If the individual with in-home lived experience is being asked to speculate about in-body lived experience, then there is a disconnect and one that should be flagged by the team and the ethics board. That said, a compelling case can be made for the ethics board to allow those with in-house lived experience to discuss their own experiences supporting someone and where they are not accessing secondary participant's knowledge or experiences. Again, early collaboration is key.

- Insufficient understanding of the complexity of FASD
  - From researchers who lack an understanding of the disability to research ethics boards that do not think individuals with disabilities can give consent, there is much room to work collaboratively and increase our collective capacities. Researchers must have a current working knowledge of the disability *and* have a nuanced understanding of the literature. We all have room to grow and learn together, but researchers and their teams need to have the background knowledge appropriate to the work at hand. Some research ethics boards can struggle with understanding informed consent when discussing individuals with cognitive disabilities. This is not a blanket statement about all research ethics boards, but it focuses on ethics boards that need to update their collective understanding of how informed consent can be obtained and the agency individuals with disabilities can be respected. There are many examples of how to engage in robust and ethical practices related to acquiring informed consent for individuals who are neurodiverse. Examples can include modified language, oral consent, ongoing consent, and explicit and ongoing dialogue about the right to

withdraw. Research ethics boards can generate deeply damaging reviewer comments while trying to attend to risk. This can stall research, but more importantly, what does PAR and other collaborative work look like when collaborators, neurodiverse, are also privy to these antiquated understandings of ability and consent. This area of scholarship and rigorous critique and strategies place a focus on thinking about new approaches to research as well as research ethics boards with a commitment to innovation and inclusion.<sup>32</sup>

## CONCLUSIONS

People with lived experience can significantly impact the way FASD research is done with their population. This is an essential moment in developing research practices with people with FASD, and there is every indication that people with FASD want and need to be involved in all the steps involved in research. While this might be a more complex process, in the end, the information garnered has the potential to be more useful in changing the everyday lives of those with FASD. This will require new approaches to collaboration, which will be new understandings of FASD with the potential to make significant contributions to PAR, neurodiversity, and patient-oriented research. Collaboration can drive innovation. However, in FASD research, this type of innovation requires a commitment to a core tenet in disability justice: leadership by those most impacted. This is a core tenet that has been largely unrealized. However, this article draws from the collective wisdom of participants at a conference to offer insights on what is needed to undertake this type of work – more widely – moving forward.

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