

WHAT IF? INCORPORATING THE VOICES OF THOSE WITH LIVED EXPERIENCE TO CHANGE THE FOCUS OF FETAL ALCOHOL SPECTRUM DISORDER RESEARCH

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ABSTRACT

How would our understanding of fetal alcohol spectrum disorder (FASD) be different if FASD research was done in collaboration with individuals with lived experience? We speculate that there would be a better balance between basic science and applied research, focusing on effective interventions and strengths. As members of the Canada FASD Research Network Family Advisory Committee and the Adult FASD Expert Collaboration Team, we provide lived experience perspectives on FASD research and assist in knowledge translation of research results. This article, written by individuals with both in-home and in-body lived experience, in collaboration with researchers, explore the importance and unique contributions of participatory approaches in broadening and shifting the focus of FASD research. We use the term “in-body” to describe the experience of individuals with FASD, and the term “in-home” refers to the experience of those who live with individuals with FASD such as caregivers, siblings, and spouses. The collaboration between researchers and people with lived experience has not only expanded the scope of FASD research, but has also helped to disseminate the information obtained through research into the hands of those who need it most: individuals with FASD and their caregivers, frontline service providers, and FASD policy makers. We believe that participatory research with individuals with lived experience will lead to the development of more effective intervention strategies, encourage strengths and resilience, and facilitate better outcomes and an enhanced feeling of support from the FASD research community for individuals living with FASD. This will, in turn, identify successes and reduce stigmatization for individuals with FASD and their caregivers.

Keywords: collaboration; commentary; fetal alcohol spectrum disorder; lived experience; participatory research

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INTRODUCTION

The focus of FASD research over the past 50 years has, for the most part, been on the causes, identification, and prevalence of FASD, as well as the brain-based deficits and negative outcomes associated with the disability.¹⁻⁷ Less attention has been paid to the impacts of prenatal alcohol exposure (PAE) on the whole body,⁷ or the experiences and challenges associated with raising or supporting an individual with FASD.^{8,9} Most importantly, there has been very little research conducted on the strengths of people with FASD and their families, effective strategies to accommodate the disability, or the factors that contribute to positive outcomes.^{10,11} Although previous researches have made a financial case for increased funding for diagnosis and specialized services for individuals with PAE and FASD, it has also inadvertently increased the stigma associated with the disability. The unintended consequence has led to an increase in feelings of helplessness and hopelessness in those with lived experience. We know from our lived experience of supporting individuals with FASD within our families, that the story of loss and deficits is only a part of the FASD story. A shift is needed to re-focus FASD research on the “person” and encourage individuals and their families to tell their stories of strength, determination, resilience, and success.

RECOGNIZING THE VALUE OF PARTICIPATORY RESEARCH

Increasing attention is being paid to the contribution of individuals with health-related concerns being involved in the development of health research agendas. In developed countries, patients are demanding a more active role in making decisions that affect them, as reflected in the principle of “nothing about me without me.”¹² This philosophy applies not only to the medical decisions about patients, but also to a broader health research

agendas. Over the last several decades, there has been a shift in the broader research landscape towards more participatory approaches and methodologies. In contrast to conventional research, participatory approaches emphasize the knowledge, perspectives, and priorities of individuals who are (or are affected by) the focus of the research.¹³ The participatory studies are conducted *with* rather than *on* people with lived experience, and with the belief that research should be done to generate knowledge for action or change.^{13,14} As such, individuals with lived experience are recognized as co-researchers, contributing equally, genuinely, and meaningfully to all aspects of the research process.¹⁵ Participatory approach to research has been applied across a wide range of settings and disciplines to increase the “real-world impact” and relevance of the research.¹⁵

For individuals involved in participatory research, these approaches can increase the engagement, empowerment, and protection, which may be especially relevant for people with disabilities.¹⁶⁻¹⁸ Even though there is an acknowledgement of the importance of engaging individuals with lived experience in all aspects of research, the voices of individuals with disabilities have largely been omitted in the development of research priorities.¹⁹ In the FASD field specifically, participatory research remains scarce, and most participatory studies have been conducted in the context of prevention.²⁰⁻²³ Although there have been some participatory studies on reducing stigma,²⁴ the experiences of caregivers,²⁵ and the physical health of individuals with FASD,²⁶ FASD research is still largely driven by academics. Our desire, as individuals with lived experience, is to encourage and participate in research that can have practical application, research that can enhance our understanding of FASD, shift perspectives, drive change, and lead to new priority areas in FASD research. We believe that this shift will lead to more meaningful and impactful research and positive outcomes for people with FASD and their caregivers, families, and broader communities.

STRATEGIES FOR INCLUDING THE WISDOM OF LIVED FASD EXPERIENCE

The Canada FASD Research Network (CanFASD) is a national interdisciplinary organization bringing together experts from across the country to address the complexities of FASD. CanFASD is actively engaged in shifting the balance of FASD research to more positive, holistic research practices, listening intently to the voices of individual with in-body and in-home lived experience. “In-body” lived experience is a term used to describe the experience of individuals with FASD. The term “in-home” refers to the experience of those who live with individuals with FASD such as caregivers, siblings, and spouses. As members of the CanFASD Family Advisory Committee (FAC) and the Adult FASD Expert Collaboration Team (AFECT), we believe in the importance and unique contributions of participatory FASD research approaches in broadening and shifting the focus of FASD research, and the value of incorporating the voices of individuals with lived experience to translate research evidence into practical and meaningful change.

Family advisory committee

Recognizing the important impact of including the voices of those living with FASD in research, CanFASD initiated the FAC in 2014. The mandate of the committee is to advise on FASD research from a caregiver’s perspective, and to assist in knowledge translation of FASD research results. The FAC is a pan Canadian committee with a maximum of 12 caregivers each, representing one of the CanFASD member jurisdictions across Canada. The committee reviews and provides input into FASD research design, implementation, analysis, and knowledge translation as requested by CanFASD. FAC members come with varied experiences not only as parents, but also as professionals in various fields including education, justice, children’s services, and FASD/disability services. Having in-home lived experience providing support, advocacy, and

mentoring to youth and adults living with FASD, the caregiver’s perspective helps keep research real and practical.

The inclusion of caregivers with lived experience in FASD research allows for careful consideration of tangible individual and family strengths, and ways in which those strengths may be leveraged to foster healthy outcomes. Inclusion of these individuals in research amplifies the voice of this population, thereby elevating their value and contribution. The future of our children is dependent on the research being done today, and as parents it is our responsibility to contribute to research that will change systems and practice going forward. A member of the FAC and co-author of this paper (WB) summed up this issue stating that: “When children are little, new parents do what they must do to ensure the safety of the child and move on to the next day. There are many parents who have parented an individual impacted with FASD, and wished they had a “do-over.” The parents learned what might work and how they could do it differently. We have very little impactful training for frontline service providers or parents, and thus lesser opportunities for learning and doing things differently. This is the research that parents and frontline service providers in the field of FASD need: applicable research that will change practice in all systems for the better.

Adult FASD expert collaboration team

The Adult FASD expert collaboration team (AFECT) was formed in 2020 based on the belief that it is essential to include the voice of individuals with in-body experience of FASD in all aspects of FASD research. The AFECT comprises of a team of individuals with in-body experience to help guide FASD research and provide an opportunity to mentor individuals with in-body lived experience as advocates in the field of FASD. This team is a group of six adults with FASD who meet monthly with CanFASD members to talk about FASD research. Each AFECT member is supported by a mentor from the FAC. The mission of the team is to advise CanFASD on priority areas of research

for individuals with FASD, and to help translate the results of the research to make sure that they are understood by, and available to the people with FASD. Examples of the priorities for FASD research identified by the AFECT are: housing issues, issues related to the medical health system, and research on sensory issues. They have identified the need for research information to be provided in plain language, which is accessible to individuals with in-body and in-home lived experience. One of their objectives is to participate in and share information about research in FASD where the voices of lived experiences are highlighted.

A member of the AFECT and co-author of this paper (LR), emphasizes on the importance of collaborating with individuals with FASD in all aspects of FASD research. She noted that as an individual who received a diagnosis later in life, she had to educate herself on what FASD is and what support she was able to obtain. As she started attending conferences and meeting others specializing in the field of FASD, she realized that a majority of scientific research was being done on animals such as mice, rats, and fish, and a lot of it did not include people who were living with the disability. She stresses on the fact that she strongly believes research really needs to begin with a person who is living with the condition. She emphasizes that people with the disability might not have all the answers, but they have an experiential wisdom that has largely been ignored, that their voices matter, and that being included matters. As an FASD advocate living on the spectrum says, “nothing about us without us.”

It is evident from this perspective that individuals with FASD are eager to participate in FASD research, and that they need to be invited to the table. By becoming involved in FASD research, individuals on the spectrum can alter the focus, making the research more meaningful and empowering individuals with lived experience. Effectively mobilizing this information can help influence policy and practice in healthcare, education, and other areas of their lives.

IDENTIFYING PRIORITIES OF THOSE WITH LIVED FASD EXPERIENCE

It is our contention that the exclusion of individuals with FASD and their families in the consultation process in developing FASD research protocols has contributed to the negative framing of FASD as a disability, and the subsequent stigmatization of those living with FASD. Glimpsing into the lived experiences provide opportunities for a balanced narrative, through which individuals may be increasingly humanized and seen for their contributions, strengths, and resiliency. Working together as co-researchers, the FAC, AFECT, and CanFASD researchers have engaged in numerous initiatives that highlight the richness and ongoing impacts of research conducted in collaboration with those with lived experience.

Since the inception of FAC in 2014, the Committee has been active in identifying the priorities for FASD research from the perspective of caregivers. In 2016, the FAC and CanFASD received funding from the Canadian Institutes of Health Research, Strategy for Patient-Oriented Research initiative, to identify FASD research priorities among parents, caregivers, frontline service providers, and individuals with FASD. The first step in this project was an online national survey, asking caregivers and frontline service providers ($n = 61$) about the types of FASD research that have been most helpful for them in the past, what aspects of living with FASD they would like to see more research done on, and what their ideal way to receive FASD research results would be.²⁷ In addition, small group follow-up discussions were held with caregivers ($n = 49$), with questions focused on support strategies, issues related to aging with FASD, and physical or health related concerns because of the frequency that these issues raised in the national survey. The project investigators analyzed data from the survey and focus groups, and collaboratively identified four themes: (1) FASD as a whole-body disorder, (2) aging and transitions, (3) strategies and supports, and (4) advocating for support.

Following the initial survey and focus groups, a 1.5 day in-person workshop was held, which was attended by caregivers, frontline service providers, and individuals with FASD. The workshop was designed to amplify the voices of those with lived experience and those who provide services to individuals with FASD and their families, and also to obtain information on their priorities for FASD research. The workshop was co-facilitated by a CanFASD researcher and a FAC member. CanFASD researchers were in attendance, but in a listener role rather than the “expert” role. This was the opportunity for FASD researchers to hear directly from a group of individuals with lived and frontline experience about their priorities for FASD research.²⁷ It was interesting to note that for some of the specific research questions asked by participants, evidence was already available. This demonstrated to us that even though research is being done in areas of interest to those with lived experience, the results are not reaching individuals with FASD, caregivers, or frontline workers in an effective way.

MEANINGFULLY INCORPORATING THE VOICES OF LIVED EXPERIENCE

The 2016 workshop fundamentally changed the way CanFASD conducted its business. Now, collaboration and consultation with individuals with lived experience has become a standard and expected part of research protocols. This collaboration has had lasting impacts, prompting several significant new areas of focus in FASD research. These initiatives have taken many different forms, including studies catalyzed by caregiver priorities and supported by researchers, and those fully led by individuals with FASD. For example, a group of three individuals with FASD, one of whom attended the workshop, developed an online survey for adults diagnosed with FASD or related disabilities, quiring a multitude of physical conditions. The translation and dissemination of this data²⁶ have helped expand the focus of FASD research to examine FASD as a whole-body disorder, exemplifying the importance

of attending to the voices of individuals with lived experience in directing the focus of the field.

Also raised at the workshop were concerns with mental health and self-medication, specifically that there was little research on the effectiveness of a variety of medications for individuals with FASD. Participants frequently reported that health-care practitioners had little understanding of FASD, and very few tools to evaluate the effectiveness of pharmaceutical and non-medical interventions, thus creating issues in the quality and continuity of care. It was with these concerns in mind that several research projects were initiated, including the development of a medication algorithm,²⁸ as well as a study currently underway, exploring the perceptions of individuals with lived experience and FASD service providers on cannabis use and its impacts on adults with FASD. Caregivers at the workshop also noted many concerns related to their need for better strategies and supports. This, as well as other factors, has prompted CanFASD to develop a comprehensive online survey, in collaboration with the FAC, to better understand the unique perspectives of caregivers and capture their wisdom about people with FASD.

Examples of participatory FASD research in action

The knowledge gained through collaborative approaches to FASD research has helped to guide many other initiatives that draw on the wisdom and priorities of those with in-body and in-home lived experience. For instance, caregivers have emphasized the need to enhance social determinants of health, including access to education, housing, and job training for people with FASD. In response, CanFASD and the FAC conducted an employment-related study²⁹ and created a guide for employment professionals to support adults with FASD.³⁰ A framework has also been developed for the Alberta government on housing individuals with FASD.³¹ Individuals with lived experience have also noted concerns about the lack of FASD-informed practice across sectors. To address this gap, CanFASD has

translated current research evidence into a series of online training programs for general FASD awareness as well as advanced training for those in the education, child welfare, prevention, and justice sectors, and a course for frontline workers on FASD best practices. Finally, acknowledging the importance of engaging with individuals with FASD and their communities in supporting healthy outcomes, CanFASD researchers developed a multidisciplinary framework for targeted and supported aspects of intervention for individuals with FASD.³² Together, initiatives like these can help to guide research and knowledge translation in ways that are more applicable and meaningful to individuals with lived experience.

WHERE NEXT? PRACTICAL IDEAS AND STRATEGIES

Individuals with FASD and their caregivers and families have a wealth of knowledge and expertise. The rich accounts of living with FASD provided by individuals, caregivers, and families can catalyze research that would help to redefine success, and to address the unique needs of those with both in-body and in-home lived experience in more practical, relevant, and strength-oriented ways. Partnering with “life experts” on FASD can not only enrich the research process, but also may improve life experiences and opportunities for individuals with FASD, those who work with and support them, their families, and the communities in which they reside.

With the collaborative participation of individuals with FASD and their caregivers in the research process, many new areas of study may be identified that would expand the scope of FASD research beyond priorities derived by the academic community. For example, if researchers asked parents of children, youth, and adults with FASD what they would do differently if they could, they would have volumes of information. If researchers asked parents when their “ah-ha” moments were, they would have a glimpse of how paradigms shift in parenting individuals with FASD. This information would

shed light on the wisdom that can only be gained through lived experience and could be used to develop resources for preparing and equipping new caregivers of individuals with FASD. Similarly, if researchers tracked individuals with lived experience over two-week periods, and identified the key points of transition, or followed parents with in-home lived experience with FASD through the first year of the child’s life, we would have enough data to develop strategies for points of transition, and rich information for supporting parenting. This kind of follow-up research gives us important insight both into the day-to-day functioning, evolving needs and strengths, and unique developmental trajectories of people with FASD, which have strong applicability for supporting individuals with FASD and their caregivers. If researchers asked individuals with in-body lived experience to share their memories, perhaps patterns of change and insight could be tracked. If researchers study a specific area – for example processing pace, receptive language, lack of filter, echolalia, or auditory verbal memory – they could provide an in-depth picture with strategies to address the related challenges. Most importantly, conducting research *with* individuals with lived experience would help researchers to communicate research findings to those with lived experience in a language and format that is accessible to them, and the information could be used to develop effective interventions.

FASD researchers must move beyond simply obtaining feedback about their research from individuals with lived experience. By working *with* individuals with lived experience, we can make the case for the importance of research that is ecologically valid and truly meaningful in a day-to-day context. Participatory research involves an active engagement of stakeholders with lived experience from the very first step, from setting out the research agenda, to choosing an appropriate methodology, collecting and interpreting data, and guiding the knowledge translation process.¹³ That said, it is important to acknowledge that some individuals with lived experience may not have previous experience with the

research process, and may not be able to fully take part without being provided information, support, new skills, and mentorship, similar to the model used with the CanFASD AFECT committee. Relatedly, it is important to not continually rely on the same group of people with lived experience. Consulting and partnering with a wide range of stakeholders will help to prevent burnout and ensure that a diversity of voices and perspectives are heard, reflecting the unique experiences of people with FASD and their caregivers and families.¹¹

CONCLUSION

What if, over the next 50 years of FASD research, we examined more of the other side of the coin. What if we looked at the possibilities, joys, and growth that happens in families who have raised, and supported individuals impacted by FASD. Research done in collaboration with people with lived experience will identify areas with a high potential to improve outcomes. It will contribute to the toolbox for individuals with FASD and for caregivers to be better able to understand the full story of FASD, not just the challenges, but also the strengths and best practices. Individuals with FASD would be able to know that their limitations in some areas do not define their path in life. Parents would be able to find unique strategies that have a demonstrated effectiveness. Spouses would be able to create relationships built on strengths, and families would naturally adapt to strengths. Frontline workers would be equipped with effective strategies and possibilities. Communities would see the possibilities in the community service provided by individuals with FASD through their dedication and commitment. Ultimately, incorporating the voices of individuals with lived experience in FASD research will help to

¹¹Additional practical strategies for establishing research partnerships with individuals with lived FASD experience have been described in another article in this issue, entitled *Nothing About Us Without Us* (Reid, Brownstone, Schofield, Pitawanakwat, & Stewart). This article summarizes the workshops conducted with individuals with FASD and caregivers to discussing the barriers to fully participate in collaborative research.

turn research into meaningful practice and contribute to tangible improvements in people's lives.

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