

Leveraging Community-University Partnerships to Develop a Strength-Based and Individualized Approach to Humanizing Housing Service Delivery for Individuals with Fetal Alcohol Spectrum Disorder (FASD)

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Article abstract

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Leveraging Community-University Partnerships to Develop a Strength-Based and Individualized Approach to Humanizing Housing Service Delivery for Individuals with Fetal Alcohol Spectrum Disorder (FASD)

**Jacqueline Pei, Cheryl Poth, Elizabeth Carlson, Vannesa Joly,
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ABSTRACT This field report summarizes and advances key learnings for leveraging community–university partnerships addressing housing service gaps for high-risk, marginalized populations with complex needs. We describe our navigation of existing and forged intersections to develop a strength-based and individualized approach to humanizing housing service delivery for individuals with fetal alcohol spectrum disorder (FASD). Our account is framed by four questions: why community and university partners came together to develop a responsive approach through the CanFASD network; who became key stakeholders in the partnership; how our humanizing housing approach is guiding the navigation of complexities inherent in service delivery for individuals with FASD; and what insights about creating intersections are we applying to our community-university partnerships.

KEYWORDS housing service delivery, community-university partnerships, marginalized population needs, housing, fetal alcohol spectrum disorder

Why: Housing as a Human Right for All Requires a Responsive Approach to Service Delivery

Adequate housing has been described as essential to one's sense of dignity, safety, inclusion, and ability to contribute to the fabric of neighbourhoods and societies (Public Research Initiative, 2005). Canada has recognized that adequate housing is a fundamental human right by ratifying the International Covenant on Economic, Social, and Cultural Rights (ICESCR) and has agreed to take appropriate steps toward realizing the rights set out in it. Yet, many Canadians struggle to secure adequate housing, and housing service gaps are especially pronounced for high-risk marginalized populations with complex needs, including individuals with fetal alcohol spectrum disorder (FASD), whose needs are not well understood in the homeless serving sector (Badry et al., 2018). FASD is a diagnostic term that refers to a broad spectrum of needs caused by prenatal alcohol exposure and the resultant injury to the developing brain (Cook et al., 2016). FASD is a life-long disability and roughly 4% of Canadians are formally diagnosed with it (Brownstone, 2005; Canada Fetal Alcohol Spectrum

Disorder Research Network [CanFASD], 2018). Because the disorder often goes undetected and can look and present differently between individuals, many lack the necessary supports to thrive in the community. Families and communities suggest that housing supports that offer a more personalized approach are more likely to support healthy outcomes for this population with complex needs.

Community organizations, in collaboration with specialized university-based researchers, have largely been leading the initiatives toward realizing the fundamental human rights set out in the ICESR. The Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD) has been a leader as the first collaborative, interdisciplinary FASD research network in the world, with partners across the nation. CanFASD engages researchers, families, graduate students, practitioners, program leaders, frontline workers, and community members who receive services to advance research and service delivery—including housing supports (Badry et al., 2019). CanFASD worked with the university-based Alberta Clinical and Community Evaluation Research Team (ACCERT) to successfully partner with community members who provided the impetus to develop a responsive approach to explore the question: How might we support housing service delivery for marginalized individuals who have complex needs?

Our community–university partnership was founded on our shared beliefs that knowledge arises from multiple sources and that respecting this diversity must be a cornerstone of any work conducted. For this reason, we began by acknowledging what has been done previously in this realm, which involved reviewing existing research and listening to those with lived experience to inform our work. In our reading of literature, we sought to understand the gaps in housing services for complex populations. However, we were not limited to what might still be possible. By listening to our community and research partners, we sought to understand the gaps they perceived between research and practice for individuals with FASD. Together we started to understand the vast complexities of both the individual needs in the FASD community as well as the systematic and functional needs within the housing community. We committed to building a community-grounded place to move forward in a responsive manner. Although the description that follows is presented in a linear manner, it is important to note the iterative nature of this process as we engaged in multiple community consultations throughout this experience to harness the expertise of our community and university partners.

Who: Diversity Was Essential for Understanding the Complexities of Housing Needs and Partnership Roles

With a decade-long track record of forging successful community–university partnerships, ACCERT was well-positioned to draw from diverse and interdisciplinary expertise and experiences to advance the innovative thinking and practice this project required. A key mission for ACCERT is equipping graduate student researchers to address the complex issues they would encounter in their lifetime. For this project, our interdisciplinary team involved faculty members and students from psychology and measurement fields of study with members having expertise in neurodevelopmental research and best practices in working with individuals with FASD together with our evaluation and community-based expertise to support an

interdisciplinary framework. Team roles were diverse and, in many cases, intersected spheres of influence; for instance, Pei is both a faculty member and senior research lead for CanFASD. She acts to bridge the policy, practice, and research roles and thus helped to set the stage for this partnership to emerge.

Critically, this project and the community–university partnership were initiated by and roles negotiated with local members of the FASD community who were speaking on behalf of and with individuals with FASD. As adults, unhoused individuals are vulnerable to traumatization on the street, and many struggle with a variety of mental illnesses and substance abuse problems alongside a great deal of stress and limited social support (Hulchanski et al., 2009). In addition to the complex difficulties experienced by individuals who are unhoused, those who also have FASD may present with deficits that affect their mental health and adaptive functioning, which in turn further complicates their access to and maintenance of housing (Astley, 2004). The number of unhoused individuals who have diagnosed or undiagnosed FASD is unknown; however, frontline experts report that a large proportion of the unhoused individuals they encounter are suspected to have FASD.

Together, the core partnership team (the authors of this paper) identified key community stakeholders who were well-positioned to provide insight for addressing the following questions:

- What are the current barriers to housing success for individuals with FASD?
- What factors are associated with housing success for individuals with FASD?
- How might a knowledge of the unique cognitive functions of those with FASD better inform housing practices?
- How might knowledge of the process of providing housing supports enhance proactive responses with the FASD community?
- What has facilitated successful housing for individuals with FASD?
- How might the co-creation of solutions among experts in different fields generate guiding practices for individuals with FASD on their housing journey?

How: Our Humanizing Approach Is Guiding the Navigation of the Complexities Inherent in Housing Supports for Individuals with FASD

Recognizing the complexities inherent to the interrelated systems of local, provincial, and federal initiatives, we employed a systems framework to inform the process of developing our humanizing approach. Five activities informed the development; embedded within this approach was an iterative process incorporating emerging insights, refinements, and identifying next steps (see Figure 1).

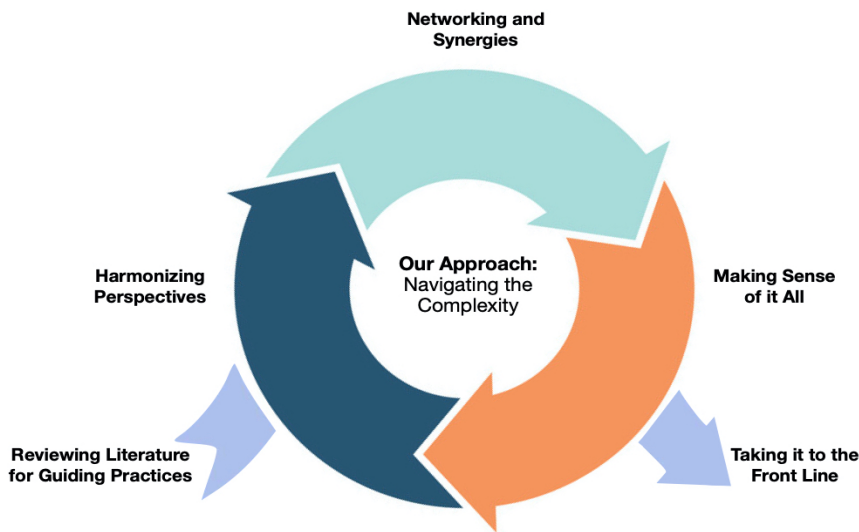


Figure 1. Five activities informing the development of our humanizing approach to housing supports.

Building upon our best practices for guiding service for individuals with FASD we completed an extensive literature review focused on guiding housing practices (Pei et al., 2021). From our review of 128 peer-reviewed articles, compelling evidence emerged for housing programs, particularly the Housing First model (Adair et al., 2017; Aubry et al., 2015; Stergiopolous et al., 2016; Woodhall-Melnick & Dunn, 2016). We identified key challenges for individuals with FASD with non-abstinence-based housing and lack of consistent and long-term support described as emerging factors related to housing tenure (Collins et al., 2012; Kirsh et al., 2011). The lack of empirically based housing research specific to or including individuals with FASD was noteworthy. There was much to learn and integrate with the knowledge created alongside our community partners about the unique needs of individuals with FASD.

Subsequently we held collaborative, multiday meetings focused on networking and synergizing that brought together relevant researchers, service providers, system planners, individuals with FASD, and caregivers of individuals with FASD to guide the group in an appropriate direction. Of particular importance was engaging individuals from two different communities of expertise—those from the FASD community and those from the housing community—to identify gaps and barriers in service delivery. The core partnership team initially identified and made contact with 66 potential attendees across Canada, with 40 agreeing to participate.

To begin, ACCERT provided a brief presentation on the state of the current research in the housing field alongside impactful presentations from community members describing the unique needs of individuals with FASD. Then the core partnership team facilitated small group discussions intentionally composed of individuals with diverse expertise and roles. Within these groups, participants tackled challenges in the field, considered strengths to be

leveraged, and were charged with producing strategies or solutions for moving forward. Finally, the groups reconvened to share, identify key themes, and advance possible actions.

Approval for the research study embedded within the networking and synergizing activity was gained from the University of Alberta's Research Ethics Board and, subsequently, all appropriate measures were followed to ensure informed consent, protect confidentiality, and lessen power issues. Data was collected using surveys, documentation from discussions, and observations. The collaborative event and the chance to be part of the creative process appeared to motivate our community members to engage in action. They expressed their frustration with the status quo and desire to move beyond dialogue to create something that could catalyze practice shifts, stating: "Enough talking, let's make change!"

Following the networking and synergizing meetings, ACCERT led the in-depth analysis and created a summary that was shared within the core partnership team. A clear understanding emerged that a new approach to housing support was needed and to do so it was necessary to move toward a strength-based individualized approach in which attaining healthy outcomes was paramount. From the community perspective, this entailed a shift from a focus on problems to be solved, as they expressed that such a deficit lens makes the issue of housing individuals with FASD seem hopeless, toward identifying success experiences that might be replicated.

Hopefulness also emerged as a key perspective within these meetings. Fueled by hope, a readiness for action was expressed: "It will take time and hard work, but it is possible." While acknowledging that "the problem is complex," participants also asserted that "there is a will to change things." The meetings were viewed as a "great start to addressing the issue of housing and FASD" in collaborative action toward a harmonizing framework—a "strong foundation on which to build together." Attendees appreciated that this meeting allowed two sectors to come together, and they stated that "working on the operations level to develop a usable framework for housing is the best way forward."

As we shared our findings with the extended partnership and beyond, the feedback we heard was that community members wanted further opportunities to engage in collaborative conversations and to expand them to include housing landlords and government officials responsible for housing policy and practices. It became apparent through our intentional/strategic connections with leaders in the homeless serving sector that we had successfully provided a safe space for the voices of community leaders to be heard on working with this vulnerable, marginalized population. We heard that conversations were continuing within communities of practice, generating ripples within the larger practice and policy communities, and creating opportunities for continued discussion. Such opportunities included our meetings with provincial health services to explore the synergies between the work occurring between our projects. This synergistic collaboration led to us all visiting a permanent supportive housing program, successfully supporting individuals with FASD. Meetings even extended to a team who was creating a business case for housing individuals with FASD and a group considering specific architectural housing needs for programs working with individuals with FASD. Since this time, momentum for these meaningful conversations has been maintained through conferences, service meetings, and funding applications to enact and study novel ideas.

What: New Insights About Creating Intersections Guide a Responsive Approach to Housing Service Delivery

Contributions to the community from this work continue and the work and the synergies generated continue to influence practice and establish conditions for forging relationships that are bridges for innovation and community empowerment. We were also fortunate that the project timing aligned with government initiatives in which housing initiatives had been prioritized, thereby creating conditions for this work to align with policy and practice initiatives.

People Create Essential Intersections for Community and University Partnerships

Careful consideration in identifying and engaging key community and university stakeholders as well as clarifying our philosophy of practice at the outset was essential. This consideration allowed the partnership to engage with genuine curiosity and honour diverse perspectives essential for solving challenges related to housing and FASD. The community stakeholders were comprised of individuals from various backgrounds whose experiences and positions provided them with unique abilities to support the intersection of ideas in different ways.

Four key partnership roles emerged, each with unique characteristics: brokers, visionaries, innovators, and experts. Whereas the professional links of brokers within both the university and community settings afforded unique synergy opportunities, the willingness of visionaries to take risks while imagining different outcomes was integral in creating and upholding a safe space for shared discovery. Similar to visionaries, the willingness of innovators to try new things and think differently about their work in pursuit of optimized outcomes helped find new approaches to long-existing challenges often experienced by those with experiences related to housing instability and FASD. The valuing and recognition of those with lived experience as experts alongside researcher expertise allowed the final outcome to be relevant and applicable in the real world. Together the brokers, visionaries, innovators, and experts created intersections of ideas, experiences, and practicalities to imagine novel solutions based on existing knowledge and practices without being hindered by those same things.

Intentionality Creates Processes Conducive to Intersections of Ideas

By integrating diverse stakeholders and generative methods we were able to create intersections among ideas to advance our thinking; for example, combining the literature review with the content obtained in meetings moved us beyond traditional research evidence. The complexity of the presenting issue and lack of evidence to guide us required that we be innovative in our thinking by seeking evidence that might be obtained through opportunities for generative and integrative thinking. Systematic and ongoing data collection, in which all data was viewed as equal and meaningful, allowed for ideas to emerge based on consensus or emphasis rather than source. This approach contributed to credibility at all levels and reduced perceptions of valuing based on educational level or social/professional position.

As co-creators of knowledge, we created a safe space where everyone was equal in their learning, and it was safe to “not know.” In this setting, filling information gaps became the goal rather than the exception. The ensuing respect was characterized by expressions of appreciation

between all attendees—many of whom quickly advanced from strangers, in some instances from two divided groups (i.e., housing and FASD, or families and support providers), into an integrated team within which each voice was necessary, valued, and respected.

Operating from a well-defined guiding philosophy, we spoke to the shared valuing of lived experiences, practical knowledge, and traditional research. We sought equity and balance during meetings. Small, diverse groups afforded each participant a position of relative expertise that fostered their willingness to contribute. We recorded all information provided and identified emergent themes and core ideas, which were integrated into the report then distributed for feedback. Through this process and with ongoing interactions with our stakeholders, we employed a process of negotiation, proposing, and altering in response to feedback. We quickly realized that we did not need to include every idea, but that we did need to include *some*. It was necessary that we take a stand and produce content that allowed stakeholders to see their voice and to suggest changes. We learned that co-creation requires some degree of structure and support to leverage the wisdom of the larger communities in strategic ways.

Momentum Creates Ongoing Opportunities for Expanding Intersections

In taking our housing framework beyond the project, we faced the most daunting challenge: distributing the materials in a meaningful way to facilitate uptake. Fortunately, we had set the tone for partnership and engagement that are foundational to this element. In our collaborative work, we were informed that a large document is rarely accessible to community members. Even though team members might appreciate the content; turning it into actions was another matter. Thus, we learned the importance of having component parts to our final project. Based on our process of co-creation, we generated stand-alone materials that allowed for program users to best access the information they needed within their program. This promoted tailoring of content and continued co-creation and engagement of the community as stakeholders identified key elements. Additionally, recognizing the power of our stakeholder group, we named all partners who participated in the document's development and ensured they received a copy of our findings that they could share; thus, increasing the probability that the contents would be more widely communicated. In essence, we shared ownership and empowered stakeholders to become advocates to continue building the community of practice that was catalyzed during this developmental process.

Conclusion: Successful Community–University Partnerships Require Readiness

The readiness of a community of partners, their willingness to engage in a collaborative process, and their commitment to move forward created the necessary synergies for innovation and impact around housing solutions for individuals with FASD. In particular, this partnership benefited from the political landscape of 2019 wherein the Governor General signed into law Bill C-97, which contained the *National Housing Strategy Act* and the federal right to housing legislation. A key outcome is the legislation creating new accountability bodies that will proactively monitor implementation of the right to housing and can investigate systemic barriers to accessing housing.

Relational approaches to housing demonstrate understanding of the complex interplay of individual, relational, societal, cultural, and historical factors that have resulted in the individuals' experience of being unhoused and allows for a true connection to be made so that person-centered work can occur. The interconnected nature of all that surrounds housing needs was reflected upon by community experts who not only called for systems-level change but were willing to become agents of change themselves. Together we learned that we do not always need to do more, we need to do it differently and without truly listening to one another we will persist down the wrong path. We understood the necessity of shifting from conventional, depersonalized categorical approaches to housing service provision and evaluation to instead offering a harmonizing, translational, relational, person-centered, process-oriented, and systems-informed approach for practice.

About the Authors

Dorothy Badry is a professor in the Faculty of Social Work, University of Calgary with 16 years in child welfare. Research focus includes FASD and child welfare issues, suicide prevention in FASD, disability, FASD prevention, housing and homelessness, post-secondary education on FASD and child advocacy.

Elizabeth Carlson is a school and clinical child psychology graduate student at the University of Alberta. Elizabeth takes a collaborative, wholistic, and strengths-based approach to working with youth with complex needs. She strives to learn ways of improving assessment practices to best serve youth and their families.

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Tracy Mastrangelo has focused her career in the social work and education fields. Her work has focused primarily on supporting families and children/youth with complex needs through relational approaches to support individual success. Tracy has a Master's degree in Interdisciplinary Studies with a focus on psychosocial interventions in school communities.

Danielle Mattson is a PhD student in the University of Alberta's School and Clinical Child Psychology program. She is also a member of the ACCERT research team and is particularly interested in studying mental health and the factors that contribute to positive psychosocial outcomes for youth with complex needs.

Audrey McFarlane is the Executive Director for the Canada Fetal Alcohol Spectrum Disorder Research Network. She was one of the founders of the Lakeland Centre for FASD and led this organization for almost 20 years. As the Executive Director of the national research network in FASD, she directs and encourages research in areas of FASD that is meaningful to families, individuals with FASD, policy makers, service providers and to promote healthy pregnancies.

Richard Mugford has spent his career developing and managing programs addressing homelessness for youth, families, and individuals, as well as programs that support individuals and families living with an FASD.

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