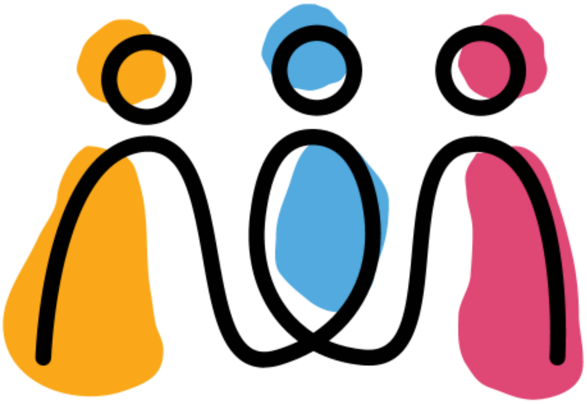
the Belonging project

Belonging from the Perspective of People with Intellectual Disability

UNIVERSITY OF ALBERTA

This simple summary explores what it means to belong from the perspective of people with intellectual disability.



This is a plain language interpretation of the published journal article titled *Belonging involves mutuality, agency, and acceptance: A participatory ethnographic exploration of belonging with five adults labelled with intellectual disability*. This is one in a series of briefs co-produced from The Belonging Project, an inclusive research project exploring belonging with people with intellectual disability.

ABOUT THE BELONGING PROJECT

An inclusive research partnership between Skills Society and the University of Alberta, The Belonging Project explored the conditions, processes, and actions that support opportunities for belonging in the lives of people with intellectual disabilities.

LEARN MORE ABOUT THE PROJECT ON OUR WEBPAGE:
www.skillssociety.ca/projects/the-belonging-project

SKILLS SOCIETY

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Introduction.

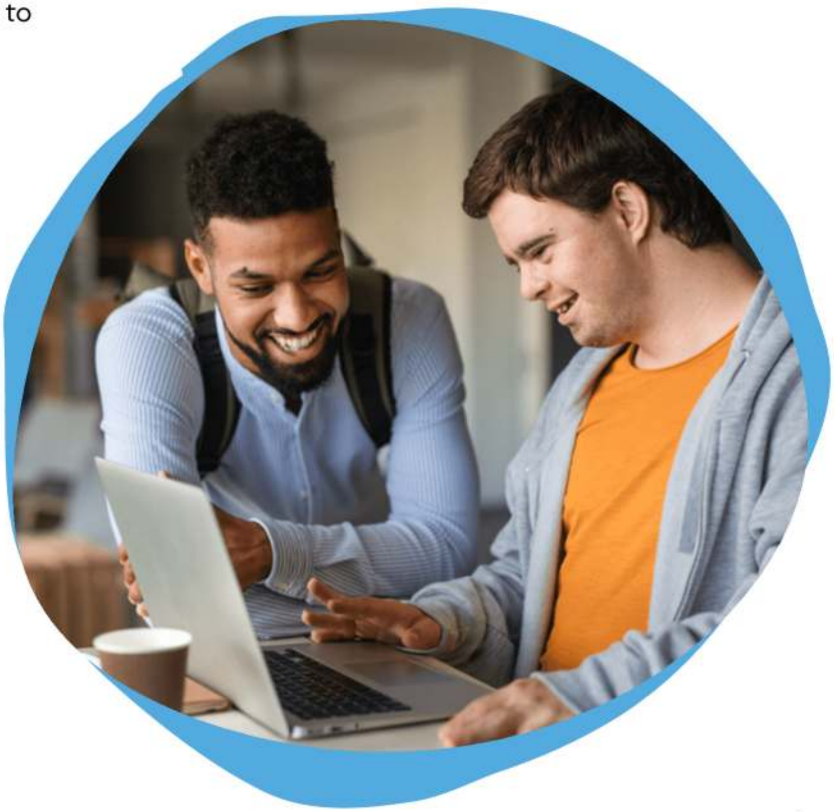
Supporting belonging in the lives of people with intellectual disability is an important goal of policy and practice. Yet, many people with intellectual disability and their allies tell us that they face barriers to finding belonging and that they are lonely and socially isolated. One part of helping to get more belonging in people's lives is to better understand what it means to belong. This simple summary explores what it means to belong from the perspective of five people with intellectual disability living in Alberta.

What We Did.

The Belonging Project was an inclusive research project that explored belonging with five adults with intellectual disability. Each of the participants talked to researchers in an interview at their house, shared stories from their life, gave a tour of their home, and chose up to four spaces or relationships of belonging they wanted to explore further in a go-along style interview. Participants took researchers to all kinds of places including a community kitchen, places they volunteered and worked, a bowling alley, and coffee shops. Participants also introduced researchers to their partners, friends, support workers, and family members. Researchers also interviewed nine policy, advocacy, and service provider leaders.

Researchers had ethics approval from the University of Alberta. Researchers recorded what was shared and used the information to write three journal articles that are published in academic journals. The researchers also worked with community leaders to create simple summaries of each article (like this one!) and other tools and training materials for support workers.

The researchers recognized the ways research has sometimes been used to harm people with disabilities in the past. The researchers were careful in the design of the project to make the process as inclusive, welcoming, and safe as possible. The researchers are also doing their best to make sure what was learned from the project is made accessible to different people including the participants, other people with disabilities and their allies, service providers, and other researchers.



Meet the People Behind this Project.

This project was a shared endeavour that involved collaborative exchange and reciprocity in the co-creation of knowledge.

MEET THE CORE PARTICIPANTS

Christine, Jonah, Kevin, Sarah, and Cara have an intellectual disability and shared their experiences of belonging. They helped shape the research process by choosing where we did go-along interviews, identifying others we should connect with, including support workers, friends, and family members, and helping determine what happened with the art created during the creative workshop.

Christine[1] is an articulate young woman and animal lover who enjoys watching professional wrestling and hanging out with her fiancé.

Kevin is a self-described ‘people lover’ who is passionate about drama and takes pride in giving back to his community.

Jonah is a sensitive and caring young man who values his friends and family and enjoys bowling, video games, and volunteering in his community.

Sarah is a fierce self-advocate and problem solver with a vibrant, free spirit and love of visiting over a hot cup of coffee.

Cara is a soft-spoken and friendly artist who loves to paint and draw and share her warm energy with others.

MEET THE POLICY, ADVOCACY, AND ORGANIZATIONAL LEADERS

Iris, William, Laura, Tyra, Julia, Deanne, Samesh, Charles, and Declan are leaders currently working or recently retired from the disability services sector. They shared their experiences and thoughts on what supports and hinders belonging in one-on-one interviews with researchers.

MEET THE PARTNER COMMUNITY ORGANIZATION

Skills Society is a not-for-profit rights and service organization that provides daily living supports to adults with intellectual disability. Leaders were involved in shaping the research questions, supported participant recruitment, and were partners in the design and dissemination of community-based knowledge products.

MEET THE RESEARCHERS

Paige Reeves was the lead researcher who stewarded this project as part of her PhD work at the University of Alberta. She drew on her knowledge of qualitative research, strong connections in the community, and her experiences as a sister, friend, and paid support to people with intellectual disability in the design and implementation of this project.

Shanon Phelan and David McConnell, researchers at the University of Alberta and Dalhousie University, supervised and mentored Paige. They have been doing research in the family and disability field for over forty years combined and have lived experience as caregivers and advocates for people with intellectual disabilities.

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[1] Pseudonyms have been used throughout to maintain participant confidentiality.

What we learned.

This paper tried to answer the question:
How is belonging experienced by adults with intellectual disability? We explored things like how belonging felt to people with intellectual disability, how they know they belong somewhere, and how belonging showed up in their life. We learned about the things that helped belonging and the things that got in the way of belonging.

MUTUALITY: BELONGING INVOLVES SHARED EXPERIENCES AND FEELINGS

Participants with intellectual disability told and showed researchers that belonging is something that they felt and something that they created with others. When asked about where they feel a sense of belonging, participants shared activities they did with others like: watching a favorite show, bird watching, going for coffee, window shopping, or bowling. Something that was important to participants was that they felt valued and recognized by others. For example, Jonah spoke with great pride about his volunteer work at the foodbank, saying this is a space of belonging for him because others recognized and valued his contributions.

Participants also talked about what not belonging felt like. They named feelings like rejection, underestimation, judgement, loneliness, and self consciousness as signs that they did not belong somewhere. For example, Christine shared a story about how she often feels judged when out in public and how this makes it hard for her to feel like she belongs:

Christine:
Sometimes for me I honestly think they do [judge me]...I'm not stupid, sorry to use this word, but I'm not stupid. I may have written all these things wrong but I just wish people would give me more of a chance...

Drew, her fiance:
To prove?

Christine:
Well and not just to prove but to talk to me like I'm an adult. I'm not some 4 year old kid. I can handle it. If I don't understand a word, I will tell you.

AGENCY: OPPORTUNITIES TO MAKE CHOICES AND DIRECT YOUR LIFE

All of the participants with intellectual disability talked about and showed researchers that agency was important to them. Agency meant having chances to make choices about their life and opportunities to share their thoughts and opinions with others in spaces and relationships.

While opportunities for agency were shared, more often, participant agency was constrained. Limited income, funding and support; inaccessible built environments; and barriers to reliable transportation, all constrained housing options, travel opportunities, leisure pursuits, and relationships.

For example, Jonah could not have his girlfriend over because his house is not wheelchair accessible. Sarah described how she could not visit her sister because she lived in a community that the local accessible transit did not service. And limitations of support systems meant participants had to live with at least two others who experienced disability to access support. This limited choice in where and with whom they lived and constrained activity outside the home, requiring them to coordinate schedules with roommates.

Agency was also limited by the values and beliefs of support staff, family members, and guardians. For example, a common point of tension between participants and guardians was romantic relationships. Christine, Kevin, and Cara all expressed a desire to deepen their romantic connection with someone, however limits set by their guardians prevented this: Christine was unable to have sleepovers with her fiancé, Kevin was not allowed to date, and Cara was not allowed to move in with her long time romantic partner who she called her husband.

ACCEPTANCE: RENEGOTIATING SOCIAL NORMS

For all participants, their belonging experiences involved others' embracing their diverse ways of being, moving, and communicating. Although acceptance was sometimes organically present in participant's lives, it often needed to be negotiated and involved resisting and renegotiating social norms. Participants challenged social norms in the ways they communicated and moved. For example Kevin loves to share his ideas and opinions with others and spoke with high intensity for long lengths of time leaving few opportunities for his conversation partners to share their perspectives, often leaving them frustrated or feeling left out. In another example, a store clerk got frustrated with Sarah as she took longer to orient herself, place her order, and get her money to pay.

Support workers played an important role in negotiating norms - educating community members about disability and helping core participants understand social expectations in different spaces. Participants also actively resisted exclusionary norms through acts of self-advocacy and standing up against bullying and abuse aimed at people with disabilities.

Finally, in spaces of belonging, participants were witnessed to renegotiate norms with others, resulting in alternative expressions of norms that were more accepting of their experience of disability. In spaces of belonging, friends, community members, intimate partners, and acquaintances were observed to embrace a slower pace, plan flexible or adaptable activities, tolerate imperfection, or be partners in flexible and supportive conversation patterns.

WHAT GOT IN THE WAY OF BELONGING?

While participants shared that belonging is important to them, they often had trouble identifying places and relationships they felt a sense of belonging. For many participants they felt belonging only with close family, in their home, and with their romantic partners. Often when outside of their homes, participants told and showed researchers how they can be physically present but still feel socially distant and disconnected from others. Many barriers made it difficult for participants to create belonging with others. Some of the barriers they showed and told researchers about were: the inaccessibility of public buildings and houses; unreliable and inaccessible transportation options; rigid funding and support systems; having to live on a very limited budget; and strict rules or discriminatory beliefs from community members, support workers, guardians, or parents.

WHAT CAN WE DO?

This research showed it takes collective efforts to support belonging in the lives of people with intellectual disability. It is not just about people with intellectual disability 'fitting in', it is also about everyone taking actions to make our communities inclusive so people feel like they can come 'as they are'. Some big and small actions people can take to support belonging include:

- Supporting people's autonomy and creating space for them to be the leaders of their lives, to make choices and decisions, and to have control over their lives
- Being flexible, patient, and open to different ways of communicating, moving, and being in the world

- Challenging discriminatory actions, words, and beliefs
- Including people with intellectual disability in design and engagement processes so that their perspectives are considered from the outset of a project rather than after the fact or not at all
- Reflecting on our own assumptions about disability and inclusion and challenging ourselves to shift our perspectives when they are exclusionary
- Say hi, smile, and acknowledge the people with intellectual disability who live, work, and play in our neighbourhoods and workplaces
- If a business owner, create opportunities for people with intellectual disability to work in your business
- Be open to people with intellectual disability being a part of the same clubs, recreation opportunities, and activities that we are all part of and help find meaningful roles and ways for them to contribute in these spaces and activities

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