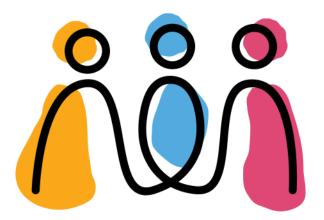


Inclusion and belonging are identified as important goals by people with disabilities, their families, and allies. And yet it is not always clear what we mean when we say 'inclusion' and 'belonging'. The purpose of this simple summary is to explore what 'inclusion' and 'belonging' can mean and what their relationship is to one another.



This is a plain language interpretation of the published journal article titled: *The (Radical) Role of Belonging in Shifting and Expanding Understandings of Social Inclusion.* This is one in a series of briefs co-produced from The Belonging Project, an inclusive research project exploring belonging with people with intellectual disabilities.

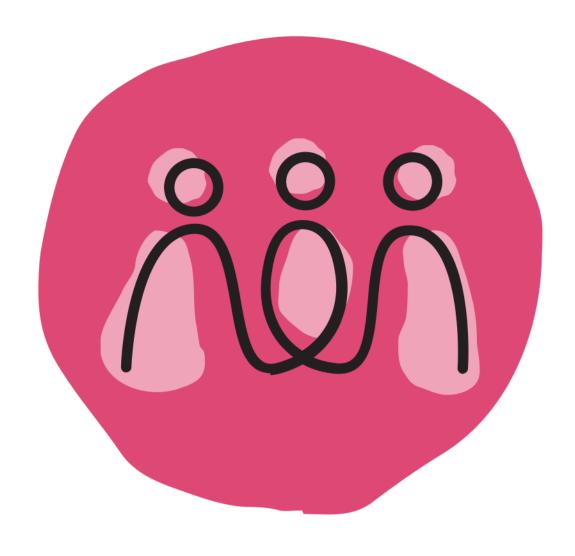
ABOUT THE BELONGING PROJECT

An inclusive research partnership between <u>Skills Society</u> and the University of Alberta, <u>The Belonging Project</u> 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







Belonging.

WHAT IS BELONGING?

"...when people feel like they belong they feel like they can be themselves and they do not have to change themselves to 'fit in'"

Belonging is unique to each person but generally people share that belonging involves feeling valued, comfortable, and 'at home'. It is often talked about as reciprocal, meaning it is co-created between a person and someone or something. You can feel belonging to varying degrees. For example feeling 'in place' versus feeling a deep, emotional, or moving connection to someone or somewhere. You can also feel belonging to multiple types of places, spaces, or people. For example you might experience belonging to your family; your neighborhood; your city; your country; or in the broadest sense to humanity. Sometimes belonging is talked about as an experience of inclusion, it is something that is felt. Others cannot say if someone belongs or not, it is something that a person has to determine for themselves based on how they feel.

In other inclusive research projects, people with intellectual disabilities have identified the following as important parts of belonging²:

 Being a member of the community who is valued and who contributes Having places to go that feel safe, comfortable, and friendly

Belonging is unique to each person but generally people share that belonging involves feeling valued, comfortable, and 'at home'. It is often talked about as reciprocal, meaning it is co-created between a person and someone or something. You can feel belonging to varying degrees.

Importantly across definitions of belonging from people with intellectual disabilities there is emphasis on being accepted for who you are, as you are. Said another way, when people feel like they belong they feel like they can be themselves and they do not have to change themselves to 'fit in'. In inclusive research, people with intellectual disabilities also shared that unlike inclusion, they can feel a sense of belonging in many different types of spaces, even those spaces where there are only other people with disabilities.

WHY DOES BELONGING MATTER?

Belonging is really important for all humans. We are social beings which means we need friendships and connections to others to be happy and healthy. Researchers talk about belonging as a critical human need - something we need almost as much as we need food or water³! When we do not feel like we belong, and when we feel lonely, our mental and physical health can suffer.

¹Reeves, P., McConnell, D., & Phelan, S. K. (2022). The (radical) role of belonging in shifting and expanding understandings of social inclusion for people labeled with intellectual and developmental disabilities. *Sociology of Health & Illness*, 1–14.

² Nind, M., & Strnadova, L. (2020). Belonging for people with profound intellectual and multiple disabilities: Pushing the boundaries of inclusion. Routledge.

³ Baumeister, R. F., & Leary, M. R. (1995). The need to belong: Desire for interpersonal attachments as fundamental human motivation. *Psychological Bulletin*, 117(3), 497-529. https://doi.org/10.1037/0033-2909.117.3.497



Inclusion.

WHAT IS INCLUSION?

Social inclusion is an important right named in the Convention for the Rights of Persons with Disabilities⁴. In research, social inclusion is commonly talked about as having different friendships and connections with others and opportunities to participate in your community that are meaningful and interesting to you. Inclusion is also talked about as important to supporting well-being^{5,6}.

WHY IS INCLUSION AN IMPORTANT GOAL FOR PEOPLE WITH INTELLECTUAL DISABILITIES?

There is a long history of exclusion of people with intellectual disabilities in Canada and Alberta. Not too long ago, people with intellectual disabilities faced horrible harms such as forced sterilization, living in institutions away from family and friends, and widespread discrimination from others. In Alberta, in the 1970s, deinstitutionalization started, led by self advocates, families, and allies.

These brave leaders were some of the first to fight for inclusion recognizing people with intellectual disabilities deserve the same rights and opportunities as anyone else. Today, although a lot of progress has been made since times of institutionalization, people with intellectual disabilities are still often on the fringes of their communities - physically present but disconnected from peers and community members.

INCLUSION TODAY, DOES NOT ALWAYS RESULT IN BELONGING

Despite fierce efforts from self advocates, family members, allies, and service providers over the last several decades, people with intellectual and developmental disabilities still often share that they don't feel a strong sense of belonging in their communities today⁷. In research people with intellectual disabilities around the world have shared how they continue to encounter discrimination, bullying, and abuse in community spaces^{8,9}. People have also shared that they do not have as many friends as they would like and often feel lonely¹⁰.

⁴ United Nations. (2006). Convention on the rights of persons with disabilities. *Treaty Series*, 2515, 3. http://www.un.org/disabilities/

⁵ Cobigo, V., Ouellette-Kuntz, H., Lysaght, R., & Martin, L. (2012). Shifting our conceptualization of social inclusion. Stigma Research and Action, 2(2), 75-84. https://doi.org/10.5463/SRA.v1i1.10

⁶ Simplican, S. C., Leader, G., Kosciulek, J., & Leahy, M. (2015). Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation. Research in Developmental Disabilities, 38, 18-20. https://doi.org/10.1016/j.ridd.201410.008

⁷ Merrells, J., Buchanan, A., & Waters, R. (2018). The experience of social inclusion for people with intellectual disability within community recreational programs: A systematic review. *Journal of Intellectual & Developmental Disability*, 43(4), 381-391. https://doi.org/10.3109/13668250.2017.1283684

Strnadova, I., Johnson, K., & Walmsley, J. (2018). "...but if you're afraid of things, how are you meant to belong?" What belonging means to people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, 31(6), 1091-1102. https://doi.org/10.1111/jar.12469

Power, A., & Bartlett, R. (2018). 'I shouldn't be living there because I am a sponger': Negotiating everyday geographies by people with learning disabilities. *Disability & Society*, 33(4), 562-578. https://doi.org/10.1080/09687599.2018.1436039

Milner, P., & Kelly, B. (2009). Community participation and inclusion: People with disabilities defining their place. *Disability & Society*, 24(1), 47-62. https://doi.org/10.1080/09687590802535410

A FOCUS ON RIGHTS HAS GOTTEN PEOPLE 'IN THE DOOR' BUT HAS NOT ALWAYS NURTURED BELONGING

Inclusion efforts have often focussed on the "formal and contractual", things like advocating for changes to policies, legislation, and regulations so that people with intellectual disabilities have the same rights and opportunities everyone else¹¹. This focus is essential and has resulted in many important improvements in the lives of people with intellectual disabilities, for example: the creation of service providers, more accessible built environments, more accessible transportation, and income assistance. Inclusion efforts are the reason people with disabilities have the right to live in community alongside their neighbours and work. That said, inclusion efforts sometimes have not been as good at nurturing and supporting informal relationships (relationships with friends and family) amongst people with and without disabilities. Rights can get people in the door but they can not necessarily guarantee that someone will be welcomed as a friend, neighbor, or colleague once they are included or 'allowed in'.

WE NEED TO THINK CAREFULLY ABOUT 'WHAT' PEOPLE ARE INCLUDED INTO

Academic writers Graham and Slee, offer an intriguing and important question: when we think about inclusion we must consider, into what do we seek to include?¹². What these authors, and other critical writers, are trying to get at are the invisible assumptions we collectively make about what is considered a 'good', 'desirable', 'healthy', or 'happy' life.

There are generally some things we know that help support a good life (for example having your basic needs met, a living wage, people who love and care about you...) but we need to be mindful not to make assumptions about what a good life looks like for someone. A 'good life' can take many different forms and is unique to each individual. Sometimes when we are supporting people's inclusion, we can make assumptions about what people want to have and do. Sometimes these assumptions can be problematic and actually make people feel more excluded rather than included. It's important to ask ourselves:

Are our communities places that are actually welcoming to people with disabilities as they are? Or do people feel like they have to make themselves change to 'fit' in a particular way?

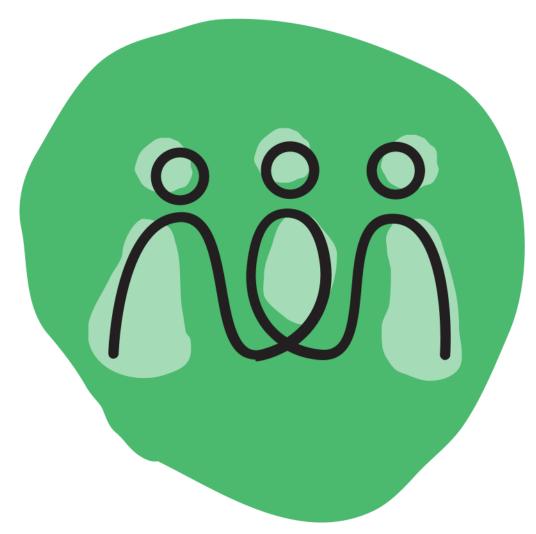
An inclusion that supports belonging requires changes on both sides - the person seeking inclusion must negotiate norms within the space, but the space/group that is including someone must also be willing to shift and evolve their practices, routines, and norms to help that person find a comfortable fit.

¹¹ Reinders, J. S. (2002). The good life for citizens with intellectual disability. Journal of Intellectual Disability Research, 46(1), 1-5. https://doi.org/10.1046/j.1365-2788.2002.00386.x

¹² Graham, L. J., & Slee, R. (2008). An Illusory Interiority: Interrogating the discourse/s of inclusion. Educational Philosophy and Theory, 40(2), 277-293. https://doi.org/10.1111/j.1469-5812.2007.003331.x

For example, our Western culture values work and productivity a lot. But how might this emphasis on working and productivity make someone who experiences intellectual disability, and for whom work might not be a desirable nor possible goal, feel? Holding the assumption that someone's worth is tied to their ability to be productive can devalue some people and make them feel less than and excluded. On the other hand, also valuing interdependence and interconnectedness, can create space for people who rely on others more, to feel valued and included and reminds all of us of the ways we all live interdependently.





How are inclusion and belonging connected?

Inclusion and belonging are often talked about together. Sometimes they are talked about as the same thing. Sometimes people talk about how inclusion can lead to belonging. Other people talk about belonging as one part of inclusion. Here we are going to talk about them as two different concepts that are closely connected and when thought about together, can make each other stronger.

USING BELONGING TO UNDERSTAND, DO, AND MEASURE INCLUSION DIFFERENTLY

Belonging, because it is anchored in the *experiences* of people with intellectual disabilities, can help us 'see', 'do', and 'measure' inclusion differently. As described above, although inclusion is well intentioned, it's not achieving all we hoped it would. People still aren't feeling a sense of belonging in their communities. People are physically present but disconnected from friends and others. There is a need to continue to learn and evolve the way we understand and support inclusion so that people can feel a sense of belonging to their communities.

UNDERSTANDING INCLUSION AS A SHARED RESPONSIBILITY

For a long time inclusion has been wrongly assumed to be the responsibility of the person with a disability seeking inclusion. For example a common idea is that if someone just does enough social skills training then they will finally be 'ready' to be included in community. When we consider belonging, which requires that a person feels they

can join as they are, we can see that this assumption needs to shift. When belonging is centered, inclusion is seen as a shared responsibility - all parties involved in the relationship must work together to find a 'fit'. From this perspective we can see inclusion as a 'learnable skill' that can be developed by both people with intellectual disabilities and people without disabilities. We all have a part to play in creating inclusive communities.

CONSIDERING THE EXPERIENTIAL AS WELL AS THE OBJECTIVE WHEN MEASURING INCLUSION

Inclusion has commonly been measured in mostly 'objective' or 'countable' ways. For example, the extent to which someone experiences inclusion has often been measured by counting the number of relationships they have or how often they leave their house to interact with people without disabilities. Although looking at how many relationships and opportunities for social interaction someone has is one important part of understanding their inclusion, it is not the whole picture and can lead to a 'facade of inclusion' where people are told they are included when they still do not feel included. Instead of only focussing on 'objective' measures of inclusion, we can also incorporate experiential ways of measuring

¹³ Valentine, D. (2020). Shifting the weight of inaccessibility: Access intimacy as a critical phenomenological ethos. Puncta, 3(2), 76-94. https://doi.org/10.5399/pjcp.v3i29

inclusion. For example we can talk to people (or observe their body language if they do not use language) to learn from them about their experiences, or use arts based ways of exploring what belonging means to them and how it shows up in their life (e.g. photography, video, or drawing). These alternative measures of inclusion can help capture meaning and experience and can help us gain a more well rounded picture of someone's inclusion and belonging.

the opportunity to have friends, colleagues, and neighbors who know, value, and enjoy being with you. Unfortunately, securing rights for people, does not necessarily guarantee they will also gain these important informal relationships. While advocating for equal rights is important, we must also collectively work together to shift social, cultural, and attitudinal barriers if we want our communities to be truly inclusive.

SEEING INCLUSION AS ROOTED IN RELATIONSHIP

"We create space and include people with [intellectual disability] as citizens in our institutions [e.g. neighbourhoods, laws, healthcare], but do we also include them in our lives as human beings?" 11

Inclusion has often been thought about as being included in the formal parts of our society - the right to work, to live in a house in a neighbourhood, to access community resources and amenities alongside everyone else. Although these parts of inclusion are very important, belonging helps us see there is another layer to inclusion that should not be forgotten -



It's a both/and.

We think we need both inclusion and belonging. We think it's helpful to think of inclusion and belonging as separate but connected because:

- If we only focus on a rights based inclusion, we can fail to nurture and support informal relationships (e.g. friendships).
- If we only focus on belonging we can lose sight of broader systems and focus too much on how someone feels. This can result in people getting 'stuck' in doing the same thing for too long or not being able to imagine more for themselves. For example people in institutions might have reported feeling a sense of belonging because this was all they ever knew and it was familiar to them, but if we take a more systems perspective we can see how problematic and wrong institutions are.
- Inclusion and belonging often require
 different approaches and strategies to
 support. For example helping someone get
 included in an activity might require some
 behind the scenes advocacy and education.
 But supporting their belonging during the
 activity might require the support to act as a
 connector and 'social bridge' helping the
 person have conversation and connect with
 others in the space.
- Inclusion and belonging each have beauty and if they are kept separate we can see the beauty and limitations of both. Sometimes this gets lost if they are merged into one and talked about as the same thing.

FULL CITATION FOR ORIGINAL ARTICLE THIS SIMPLE SUMMARY IS BASED ON:

Reeves, P., McConnell, D., & Phelan, S. K. (2022). The (radical) role of belonging in shifting and expanding understandings of social inclusion for people labeled with intellectual and developmental disabilities. Sociology of Health & Illness, 1–14.

https://doi.org/10.1111/1467-9566.13574

THERE'S MORE TO EXPLORE!

If you liked this Simple Summary, head over to our project webpage to check out the other two Simple Summaries as well as other resources and tools we've created in this research project!

www.skillssociety.ca/projects/thebelonging-project

References.

- 1. Reeves, P., McConnell, D., & Phelan, S. K. (2022). The (radical) role of belonging in shifting and expanding understandings of social inclusion for people labeled with intellectual and developmental disabilities. *Sociology of Health & Illness*, 1–14.
- 2. Nind, M., & Strnadova, L. (2020). Belonging for people with profound intellectual and multiple disabilities: Pushing the boundaries of inclusion. Routledge.
- 3. Baumeister, R. F., & Leary, M. R. (1995). The need to belong: Desire for interpersonal attachments as fundamental human motivation. *Psychological Bulletin*, 117(3), 497-529. https://doi.org/10.1037/0033-2909.117.3.497
- 4. United Nations. (2006). Convention on the rights of persons with disabilities. *Treaty Series*, 2515, 3. http://www.un.org/disabilities/
- 5. Cobigo, V., Ouellette-Kuntz, H., Lysaght, R., & Martin, L. (2012). Shifting our conceptualization of social inclusion. *Stigma Research and Action*, 2(2), 75-84. https://doi.org/10.5463/SRA.v1i1.10
- 6. Simplican, S. C., Leader, G., Kosciulek, J., & Leahy, M. (2015). Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation. *Research in Developmental Disabilities*, 38, 18-20. https://doi.org/10.1016/j.ridd.2014.10.008
- 7. Merrells, J., Buchanan, A., & Waters, R. (2018). The experience of social inclusion for people with intellectual disability within community recreational programs: A systematic review. *Journal of Intellectual & Developmental Disability*, 43(4), 381-391. https://doi.org/10.3109/13668250.2017.1283684

- 8. Strnadova, I., Johnson, K., & Walmsley, J. (2018). "...but if you're afraid of things, how are you meant to belong?" What belonging means to people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 31(6), 1091-1102. https://doi.org/10.1111/jar.12469
- 9. Power, A., & Bartlett, R. (2018). 'I shouldn't be living there because I am a sponger': Negotiating everyday geographies by people with learning disabilities. *Disability & Society*, 33(4), 562-578. https://doi.org/10.1080/09687599.2018.1436039
- 10. Milner, P., & Kelly, B. (2009). Community participation and inclusion: People with disabilities defining their place. *Disability & Society*, 24(1), 47-62. https://doi.org/10.1080/09687590802535410
- 11. Reinders, J. S. (2002). The good life for citizens with intellectual disability. *Journal of Intellectual Disability Research*, 46(1), 1-5. https://doi.org/10.1046/j.1365-2788.2002.00386.x
- 12. Graham, L. J., & Slee, R. (2008). An Illusory Interiority: Interrogating the discourse/s of inclusion. *Educational Philosophy and Theory*, 40(2), 277-293. https://doi.org/10.1111/j.1469-5812.2007.003331.x
- 13. Valentine, D. (2020). Shifting the weight of inaccessibility: Access intimacy as a critical phenomenological ethos. *Puncta*, 3(2), 76-94. https://doi.org/10.5399/pjcp.v3i2.9

