

# Spaces of Belonging

## Research Report

by

Dr Carey-Ann Morrison<sup>1</sup>, Dr Esther Woodbury<sup>2</sup>, Professor Lynda Johnston<sup>3</sup>, Professor Robyn Longhurst<sup>3</sup>

carey-ann.morrison@imaginebetter.co.nz

estherwoodbury@hotmail.com

lynda.johnston@waikato.ac.nz

robyn.longhurst@waikato.ac.nz

1 Imagine Better

2 Disabled Persons Assembly (DPA) NZ

3 University of Waikato



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## Executive Summary

This project involved collaboration between Disabled Persons' Assembly New Zealand, Imagine Better and the University of Waikato to create new knowledges, practices and spaces of belonging. The overall aim of the project is to understand disabled people's experiences of belonging, place and community. The project addresses political struggles, exclusion and marginalisation of disabled people within everyday social, economic, and political places and spaces.

Fifteen people were interviewed about their experience of belonging / not belonging. In-depth semi structured individual and focus group interviews provide rich insights into embodiment, feelings of (not) belonging, place, and the importance of other aspects of identity, such as age, gender, sexuality, and ethnicity. The main themes are: creating disability spaces; embodied encounters in public spaces; feeling in and out of place at school; disabling workspaces; dating and relationships.

We end the report by arguing that greater attention to the spatial concept of 'embodied belonging' will assist with deepening understandings of disabled people's everyday negotiations of power and place.

## Introduction

The overall objective of this project is to understand where and why disabled people feel they belong. Starting from the perspective of disabled people and families, we have examined how feelings of (not) belonging differ across places. A spatial analysis of disability highlights the ways in which feelings of belonging and / or not belonging are always personal and social, embodied and structural, individual and collective, private and public. The project has involved collaboration between Imagine Better, the University of Waikato and Disabled Persons Assembly (DPA).

### About our organisations

DPA is a Disabled Persons' Organization (DPO). It provides an active, independent voice of disabled people, that reflects the aspirations, concerns, and rights of all New Zealanders who identify as having a disability.<sup>1</sup> DPA works with government, service providers, the media and the general public to ensure that disabled people are actively involved and contribute to decision-making processes on issues that affect them.<sup>2</sup>

Imagine Better<sup>3</sup> is a collective of disability activists, advocates and allies working to be a nationally influential thought leader, trainer, research and advocacy organisation supporting the growth and effectiveness of the disability rights, visibility and justice movements. Imagine Better is also a partner in the Family & Whānau Leadership Alliance.

The University of Waikato's mission is: "To combine the creation of new knowledge through research, scholarship and creative works with the dissemination of knowledge through teaching, publication and performance, for the benefit of society."<sup>4</sup> This includes for the benefit of disabled people. Creating inclusive spaces and an inclusive society that values disabled people as active, full and equal participants is a focus for much research.

### Research objectives

The specific aims of the project are to:

1. understand further the relationship between bodies, impairment, place, and belonging for disabled people;

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<sup>1</sup> See <http://www.dpa.org.nz/>

<sup>2</sup> This involvement is sanctioned under The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), Article 4(3), which promotes the active involvement of representative organisations of disabled people which are governed by disabled people – DPOs See <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html>.

<sup>3</sup> See <https://www.imaginebetter.co.nz/>

<sup>4</sup> See <https://www.waikato.ac.nz/about/governance/charter/>

2. highlight the ways in which disability intersects with other forms of embodied difference, such as age, gender, sexuality, and ethnicity;
3. use a methodological approach that includes disabled people within research;
4. provide recommendations and help build responsive disability support systems that incorporates lived experience.

DPA is a useful organisation through which to explore politics, identities, emotions and spaces of (not) belonging. Disabled people are often considered as not belonging or as being 'out of place' (Chouinard 1999; Kitchen 1998). They are often pushed to the peripheries, marginalised both socially and spatially (Hall 2004; 2005; Milner and Kelly 2009). Disabled people face numerous challenges to access, occupy, and use places and spaces. Built environments and transport do not often consider bodily or cognitive differences, and public information and communication is rarely available in accessible formats. Additionally, discriminatory social attitudes and behaviours are felt in particular places and many everyday spaces perpetuate able-bodied norms (Imrie 1996). DPA aims to create spaces for people to come together to form a collective or disability community and to advocate for disability rights. DPA aims to help people with diverse impairments feel part of communities and places. They advocate for disabled people's right to feel 'in place' and to 'belong'. Before we discuss the methods used in the research and participants' themes, we outline in more detail the concept of 'belonging'.

## Belonging as a lived, felt and spatial concept

The research rests on the concept of 'belonging' as it is lived, felt and experienced in relation to place. Belonging is an embodied and relational experience and as such exceeds narrow categorisations. A sense of belonging is:

based in the lived experience of inclusion and affinity, and undermined by experiences of exclusion, marginalization, and rejection. The gauge of belonging is a sensory and emotional one, based in relationship and measured through comparative perceptions and judgments of the inclusions or exclusions of others (Taylor 2009, 299).

Others have noted that to 'belong is to feel attached, to feel valued, and to have a sense of insidership and proximity to majority people, activities, networks and spaces' (Hall 2010, 56). 'Belonging', therefore, is always about daily negotiations of difference places. In this way, belonging as a concept has the potential to move beyond a simple critique of disabling power towards the construction of new knowledge that enhances understandings of difference, diversity and disability. Belonging can help widen understandings of what it means to feel in and / or out of place by drawing attention to the lived – embodied and emotional – elements. Belonging, unlike common understandings of inclusion, is not something that can be easily quantified and measured.

In disability-related social policy, 'access' and 'participation' have become the main drivers for understanding inclusion. Yet, as some disability writers suggest, this may lead to disabled people living 'in but not of' their spaces and places (Bray and Gates 2003; O'Brien 2003). Hansen and Philo (2007) comment that governments spend large amounts of time and money counting, categorising and monitoring disabled people, documenting their differences. In Aotearoa New Zealand, for example, vocational service providers are only required to supply to the Ministry of Social Development the total hours service users are participating in the wider community, with the wider community defined as any activity which occurs outside of the provider premises (Milner and Kelly 2009). While baseline quantitative data is important, it only tells a partial story of the lived experiences of being disabled. It may be easy to suggest that inclusion has been achieved by counting an increasing number of disabled people in community. It is less easy to conclude that inclusion has been achieved by asking disabled people how they feel about their experience of being in community spaces. There is a noticeable absence of the accounts of people's lived experience of being in and out of place in research and policy.

Different researchers have drawn attention to the problems of research framed around simplistic notions of inclusion and exclusion in relation to disability and a range of spaces. Holt (2004) explores disabled children's experiences of primary school in Britain. As Holt (2004) discusses, the supposition is that including children with impairments in the same school spaces as non-disabled children will unsettle disabled/abled dualism. Within the micro-spaces of individual classrooms, Holt observed the various ways disabled children are 'othered' through praise, punishment and spatial arrangements. Hall (2004; 2005) reflects on the way in which people with learning disabilities still experience discrimination within spaces in which they are supposedly 'included'. Workplace bullying was described as an example of social isolation within 'inclusive' workspaces. Milner and Kelly (2009) draw attention to the importance of being in 'segregated' disability spaces. They describe how people with learning disabilities seek out spaces of inclusion beyond mainstream spaces, such as the vocational central, where a sense of belonging can be gained. Such spaces offered a place 'to escape public gaze and respite from feeling different' (Milner and Kelly, 2009 54). This is important as it contests common assumptions that all disabled people *want* to be included in mainstream spaces.

To this end, we think a focus on 'belonging' can progress conversations beyond simple notions of inclusion and exclusion (Antonsich 2010; Mee and Wright 2009). Everyday spaces and places are a material reflection of the beliefs, attitudes, and assumptions of those that have the power to build them.

## Methods

This project came about through a shared interest in working at the intersections of research and activism. Carey-Ann and Esther connected through their respective disability rights organisations to talk about how they might work together on a research project. Lynda and Robyn are professors of geography at the University of Waikato. Their research is underpinned by attention to power, place, identity and embodiment. The goal was a collaborative project between DPA, Imagine Better and the University of Waikato that would be participant driven and would create space for disabled people to talk about the actualities of their everyday lives.

The research strategy is informed by feminist, social and cultural geography and critical disability theory. Feminist research is concerned with political commitment, critical and reflexive engagement. The principles of equality, reciprocity, collaboration, partiality, and commitment to action and social justice have underpinned the research.

This research places disabled people's experiences at the centre. Disability research invariably continues to be researcher-oriented, and based around the intentions and agendas of (non-disabled) researchers and funding agencies, rather than the subjects of the research (Kitchen 2000; Priestly et al., 2010). The knowledge of 'experts' continues to be privileged over disabled people's expert knowledge about their own lives. This research challenges the exclusion of disabled people and their concerns and expertise from the production of knowledge. Participants were able to speak about the highs and lows of their everyday lives, places that inhabit, as well as places they avoid.

Disabled people and families have been involved throughout out all stages of the research, from development, data collection and analysis. This was a deliberate move to address unequal power relationships within the research process and acknowledge the expertise disabled people hold on their own lives and community needs (Chouinard 1997; Kitchen 1999). During the planning phase, we worked with members of the DPA National Executive Committee and Secretariat to collaboratively prepare the research approach and methodology. To ensure the aims of the research reflected the needs of DPA and community, Information Sheets and Consent Forms were prepared in consultation with DPA to ensure they communicated the correct information in plain English. Prior to data gathering, ethical approval was gained from the University of Waikato Faculty of Arts & Social Sciences Human Research Ethics Committee.

The research was advertised through DPA's membership email list, Facebook page, as well as through personal networks. DPA members, including the Management Team, the National Executive Committee, the National Secretariat, regional Kaituitui, and general membership, which includes

disabled people and whānau and families, were invited to participate in two phases of research: 1) small group interviews or individual interview, 2) a focus group.

People who agreed to participate in the study were contacted by email to arrange small focus group or individual interviews. We wanted to remain flexible in our approach to ensure that the research methodology didn't prevent anyone from participating. Some people wanted to be involved, but didn't want to be part of a face-to-face focus group or interview, or did not live in Wellington.<sup>5</sup> These people were given the option of participating through Skype conversation or through written responses. In total, 15 people participated in the first phase of research, see table 1 below for a breakdown of people's involvement.

<b>Number</b>	<b>Involvement</b>
9	Small Focus Groups
3	Face-to-face individual interviews
1	Skype individual interview
2	Written responses

Table 1: Numbers of research participants

At the small group and individual interviews, participants were informed of their rights, the purpose of the study was stated, and consent was obtained. Two broad conversation starters guided discussions:

1. tell us about a place where you feel like you belong;
2. tell us about a place where you feel like you don't belong.

Small group groups and individual interviews were co-facilitated by Carey-Ann and Esther. Esther has lived experience of disability, and Carey-Ann is a parent to a young son with Down syndrome. Research shows that shared disability experience is important for creating safe space for conversation and self-reflection (Butler et al. 2012; Tuffrey-Wijne & Butler 2010). Carey-Ann and Esther contributed their experiences of non-belonging to the conversations. Research relationships based on reciprocity and trust are encouraged by feminist researchers (England 1994; McDowell 1992). Where appropriate, we incorporate their/our accounts in to the research findings.

It was a considered decision to have both Esther and Carey-Ann facilitating the focus groups and interviews. There remains debate about the role of families in disability rights research and activism,

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<sup>5</sup> Wellington was initially specified as the research location, however, several people outside of the region expressed interest in participating. We sought an amendment to the ethics application so that people living outside of the Wellington region could participate. We believed it was important that people be provided with every opportunity to share their experiences and stories of (not) belonging, if that was what they choose.



and the role of non-disabled researchers in the research process. The decision to have a disabled person and a family member co-facilitating the focus groups and interviews was an attempt to highlight the collective struggles of disabled people and families, without conflating their experiences or privileging perspectives. It serves to highlight the mutual constitution of the lives of disabled and non-disabled people, and of the disability category itself (Chouinard et al). Interviews were audio-recorded and transcribed, resulting in over 130 pages of interview transcripts.

Following the completion of the first phase of research, participants were sent a participant questionnaire asking important contextual information, including their gender, age, and race. This helped to gain a broader understanding of the group.

We had initially planned to hold a second phase of research – a focus group – where participants would come together to talk through emerging themes to ensure our analysis accurately reflected their concerns, but decided instead to send out a summary document highlight emerging themes. Having conducted the interviews and focus groups, we realised the challenge of bringing people together from different parts of the country, as well as finding times that suited everyone to meet. We were also wary of asking for more time from participants, many of whom were already juggling various commitments or introducing potentially inaccessible forms of technology to further the conversation. We therefore decided on a more informal approach where participants could, if they wanted to, provide feedback on the summary document via email, face-to-face meetings or over the phone.

Content and discourse analyses was used to scrutinise data. Content analysis drew out key recurring themes about the contested qualities of disability belonging in and to place by (Hannam 2002). We each made our way through the transcript searching for and highlighting key words related to space and place, for example, home, school, street, and work. Discourse analysis assisted with the interpretation of wider relations of social power which permeate the interview narratives and media commentaries (Hannam 2002). It allowed us to go deeper into themes in order to understand the wider social context – the underlying cultural politics of inclusion/exclusion – and how this frames experiences of disability belonging. We paid attention to the interplay of multiple scales, notably the local and the national, in the construction and contestation of disability belonging.

Central to this project, is a critical awareness of the power relations that constitute research relationships. Feminist research highlights the value and power-laden content of positionality and show that research is an embodied practice (England 1994; Longhurst 1997; Rose 1997). We each come to this research from different embodied perspectives, and this has a bearing upon the research and our interpretation of it. Like Chouinard (2000), we name “academic power and

privileges for what they are” and recognise the benefits that comes with our positionalities. Similar to Maxey (Maxey 1999), we believe that “by actively and critically reflecting on the world and our place within it, we are more able to act in creative, constructive ways that challenge oppressive power relations rather than reinforce them.” Each of our research background and interests are varied<sup>6</sup>, but we are all driven to engage in research on the body that challenges social, cultural and economic inequalities in a range of spaces. We want to use our advantageous positions and to mobilise our resources and support the co-creation of knowledges and spaces (Gibson-Graham 2008).

## Participants

Participants were a diverse group. Ages ranged from early 20s to 65 plus, and they had a range of occupations. Many of you/them (9), were in both paid and unpaid roles, in the disability sector. Some were unemployed and others work part-time. Incomes ranged from less than \$25,000 per annum to over \$65,000 per annum. An even number of participants owned and rented their houses. Five men and 10 women participated in the research.

Some participants identified as straight or heterosexual, others identified as queer or bisexual, and others chose not to specify their sexual identity. Participants had a range of relationship statuses, including married, defacto, and single. The majority of people identified as Pākehā or New Zealand European, with a small number identifying as Māori and Pacifica.

Eleven participants were disabled and four were family members of someone who has a disability. They spoke of a range of impairments and bodily differences, including: chronic illness; mobility impairment; sensory impairment; acquired and congenital impairment; mental illness; and, learning disability. Some people talked about their disability as visible and/or invisible.

## Participants talk about Belonging

The notion of belonging resonated strongly with participants. It was agreed that it was a powerful way of talking about how disabled people felt about their experience of space and place.

But the feeling – I’ve been thinking about this, and belonging’s a really good word for it – cos you just don’t. You just don’t belong when you are there on the outside and you’re not meaningfully participating (Jolene, Focus Group, 16/08/18)

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<sup>6</sup> For example, Esther has researched disabled people and transport (Woodbury 2012), Carey-Ann has done research on home, love, and heterosexuality (Morrison 2013), Robyn and Lynda research the exclusionary ways in which various forms of marginalisation and discrimination – such as sexism, homophobia, transphobia, and racism – shape people’s places and spaces (Johnston and Longhurst, 2010).

Conversations with participants revealed the incomplete and partial nature of belonging. It was talked about as a journey and as a feeling that emerges over time and across different spaces. It was described as an ongoing process of coming to feel more welcome and 'in place'. The incomplete nature of belonging means that it is fragile. People talked about times when a sense of belonging had been destroyed.

Is that like that macro and micro, right? Cos I, on a macro level, don't really notice an everyday sense of not belonging [Participant Agreement 1], but throughout my day, I have micro-aggressions of not belonging. [Participant Agreement x 2] And they build up! They build up. (Rebecca, Focus Group 16/08/18).

Something my school did, which sticks out, which was really terrible was we had our end-of-year assembly and everyone was getting certificates for various things like 'Good Citizenship' and 'Achieving Well!' in different things. My friend's name got called out, and I was like, 'Why is he getting an award? He's pretty average!' [laughter] They read out on the certificate, he literally got a certificate for being friends with me...I'm not even kidding! This was in front of 500 of our peer group (Sophie, Focus Group, 16/08/18)

They way participants engaged with and talked about belonging varied from ownership of spaces, building belonging, to feeling that they did not belong in disability (or other) spaces at all.

Dwayne: I don't feel completely comfortable in any place I go to

Esther: Do you feel comfortable in disability spaces?

Dwayne: No, no I don't. No, I'm feeling less comfortable actually.

Carey-Ann: In your Pacific community spaces, with your disability identity; how does that intersect?

Dwayne: Probably worse. (Individual interview, 18/12/2018)

It's so weird about words and what they mean, but when people say disability, I feel like that doesn't include me ... in a disability space there's nothing though that sort of signifies me. I feel like I'm interrupting this space ... I'm constantly being read the wrong way, and I think I'm just worried about being read the wrong way and ... people might not be welcoming in that sort of space. (Laura, Individual interview, 11/12/18)

Oh god, and the [LGBTQIA] acronyms always change, and I'm always like, 'oh god what letters', then I feel terrible because I don't know... I feel like I don't belong in a lot of queer spaces ... I don't think I read as very queer. (Laura, Individual interview, 11/12/18)

Participants talked of finding fleeting moments of belonging, where they might not otherwise have felt it, when out and about in general community spaces.

We came across a guy in the park the other day and he was kicking a ball around ... and then we noticed he had Down syndrome ... we were like, "Hey," ... It was a really nice interaction. So, generally, we kind of almost feel like we might smile, even if [our daughter] is not with us ... [we felt] like we're part of that; we're part of your community. (Anna, Focus group 15/10/18)

Whereas, when people strongly felt like they belonged, they knew it and expressed it in definite terms.

Carey-Ann: What about the specific spaces designed for people with disability? Do you think you have more of a sense of belonging in those spaces?

Janiqua: Totally. It's like by the time we left we like owned that place. (Focus group, 15/10/18)

Trusted relationships within disability spaces could help forge other relationships and facilitate belonging. While sometimes disability spaces were policed in a way that made participants feel they didn't belong and weren't accepted as disabled people.

Jolene: most of the time, you spend your life in a world with people – or in rooms – with people that don't have disabilities and it can be quite an isolating feeling... But ... I knew that the people that were gonna be here would be pretty – because [interviewer] had organised it [laughs] I knew it would probably be accepting ... other disability environments that I've been have[n't] been as accepting and as comfortable.

Sophie: It's like, 'prove your disability credentials'! (Focus group, 18/08/18)

Belonging, to a group or space, can be asserted and reinforced through shared knowledge and insider jokes. However, even people who were insiders and belonged, were still aware and careful of their place in relation to other disabled people within that space.

Sophie: I was like, "oh and I bring my own chair" and she was like, oh so awkward. [laughter]

Rebecca: It's funny, that classic where you get to reclaim some space – at least I do – when you make the ableds uncomfortable. [Participant agreement x 1] [laughter] Because what other fun can you have? But yeah, I love that, I want my BYO chair. Am I allowed to laugh at it? [laughter]. (Focus group, 18/08/18)

Rejection from a disability space which 'belonged' to non-disabled people, meant one disabled participant looked for belonging elsewhere and found it in rock and roll music – in a space where you belonged by 'not belonging' elsewhere.

Both these [disability] organisations told me straight to my face there is no way that we're going to employ anybody like you; we can't have people like you

working with our people. So, that's when I turned to rock and roll and never turned back. (Maurice, individual interview, 28/11/18)

Participants engaged with ideas of belonging and disability by making connections between other groups and spaces of belonging or not belonging, for example sexuality and ethnicity.

Jolene: I have a theory that there's more crossover between being queer and disabled, that ... there's such a crossover of experience of being the outsider and being not included, that I think that more and more I'm like yeah, everyone queer is disabled and [everyone] disabled is queer, obviously. [laughter]

Rebecca: I think it's 'cos you can understand fluidity and...

Esther: Complexity...

Jolene: And normality, or the way that normality is expressed in the world and how that impacts on people who are classed as 'abnormal'. (Focus group, 18/08/18)

In terms of kind of the Māori thing, it's sort of much the same. It depends on the situation you're in. I mean, the thing about me is I've got a strong Māori whakapapa but the fact of the matter is I don't look Māori; so I get racism two ways. People say all these outrageous racist things about Māori and in my presence. I strike the same attitudes with Māori when I am with Māori. I have to eventually sort of say, "I'm actually Māori too." (Maurice, individual interview, 27/11/18)

## Emerging Themes

There are five research themes that emerged from participants. These are: creating disability spaces; embodied encounters in public spaces; feeling in and out of place at school; disabling workspaces; and, dating and relationships. We discuss each of these themes briefly here and explore them in more depth in further work.

### Creating disability spaces

People reflected on intentionally created disability spaces – organisations or groups – as well as improvised spaces – disabled people who identified each other and connected in non-disability specific spaces. These spaces formed for both political and social reasons.

Then went to university, used Disability Support Services there, joined [organisation] a rep group for students with disabilities, did research into what disability was. I found my belonging that way, through finding people in the rep group and it was quite empowering to take ownership of 'yeah, I am going to have this for the rest of my life. (Rebecca, Focus group 16/08/18)

Well one of the places where I really believe I belong is at Blind Foundation meetings... That kind of I guess combination of respect and understanding goes a very long way to make me feel included... (Dave, Individual interview 05/11/18)

I was looking forward to being in a room with you guys [for the research], because I don't hang out with people with disabilities very much and particularly not people my age, and how I crave that. (Jolene, Focus group 16/08/18)

Some participants noted that disability-specific spaces help create feelings of safety and strength. Shared experience and understanding was an important aspect of these spaces.

The first time I drove there [the Independence Games], even before I got out of the car I started crying. I was so relieved. I could see all these people ... people just like us with all sorts of mobility issues and all the rest of it. All these adults around them helping them and stuff. You didn't have to explain anything; just completely accepted. (Bernadette, Focus group 10/11/18)

It was really nice to be part of this swimming group growing up it was – just that – a wonderful space where people just took me at face value and didn't have high or low expectations and didn't speak for me, but I could just go and be a kid and enjoy swimming. (Mere, Focus Group 16/08/18)

Yeah, just having people you can relate to on a different level, isn't it? They get it... They get it yeah. If you're having a bad day or something is frustrating, you don't have to hold it in and pretend. (Anna, Focus group 15/10/18)

Some people spoke about the frustration of disability spaces where accessibility and / or inclusion needs were not met, despite assumptions that they would be.

When you look at that meeting that we had at [government department], you come in and the room's quite small, and so the wheelchairs were struggling to get around, and when they served lunch they put it on a trolley right in the corner of the room about that wide with the width between, to try and get in, and none of the wheelchairs would get there. (Dwayne, Individual interview 18/12/12)

Others discussed feelings of not fitting into disability spaces. There is a concern that – because of age, race, impairment, gender etc – some disabled people are not accepting of each other. Ironically, then, some people would like to occupy disability spaces, yet they felt like they did not belong there.

Because I'm invisible and I blend, I get questioned every time I try to be in this community to the point where you're just like, 'Why bother?' (Rebecca, Focus group 16/08/18)

In a disability space there's nothing though that sort of signifies me. I feel like I'm interrupting this space ..., but it's also really hard because I have an invisible illness, so I'm constantly being read the wrong way, and I think I'm just worried about being read the wrong way, and feel like... people might not be welcoming in that sort of space. (Laura, Individual interview 11/12/18)

All of these conversations pushed beyond ideas of 'inclusion', to what did or did not create a sense of 'belonging.'

## Embodied encounters in public spaces

Public spaces - such as cafés, libraries, hobby clubs, playgrounds, pubs, and on the street – are sites of embodied encounters we have with other ‘strangers’. Conversations in public highlight people’s attitudes and reactions. Participants talked about people’s discriminatory attitudes. People staring, laughing, unsolicited offers of ‘help’, inappropriate questions about bodies, and judgement and assumptions about impairment structured these public encounters.

Do you need help crossing the road, or something like that, or just stopping me to grab me really, really tightly and pray for me and that kind of stuff and not letting go of me. Giving me cash... (Esther, Focus group 16/08/18)

But it means that people judge me on the street for having a facial palsy, and then because it’s a facial difference there seems to be a kind of a perception that, ‘Oh, you’ve got a slight facial anomaly’ – for lack of a better word – ‘that must mean that you have a learning disability’ or something like that. (Ginny, Focus group 16/08/18)

I took [child’s name] to Junglerama the other day ...there were other children there; you know, typical children. I do still sometimes feel a little bit like [child’s name] is... people will also ask, “How old is she?” or “There’s a baby,” and she’s three. So, little things like that. Then sometimes they’re like, “Oh,” and you just get that look. (Anna, Focus group 15/10/18)

Public access-needs influence feelings of belonging. It was suggested that acknowledgement of the diversity of people’s access needs - even if needs could not be met - is important for making a space feel inclusive.

Most spaces, I look at events or invites and things like that and there’s just nothing. There’s just no, ‘you’re welcome in this space. We’ve thought about the fact that not everyone has the same accessibility needs’ or that not everyone has no accessibility needs. (Jolene, Focus group 16/08/18)

## Feeling in and out of place at school

Schools were a significant space for participants. For disabled participants, it was clear that school had a huge impact on a sense of self, both as children and as adults. Memories of school – and the emotions involved – are carried into adulthood. Many people reflected back to their time at school and recounted, in detail, stories about the difficulty of ‘finding a place’ at school to belong.

You could either be part of the learning support centre or you could be part of the mainstream school. There wasn’t any other way to be or to identify... I felt a bit excluded from both. I could have tried really hard to be one or be the other, but it didn’t feel accurate. (Mere, Focus group 16/08/18)

Many participants felt that the education system is informed by a medical model of disability that prioritises therapy and intervention, at the expense of education.

My [impairment], but that's not a disability to me. It is what it is. It's been there for 25 years. It's not gonna go away no matter how many occupational therapists in primary school tried to make me blow a ball across the room without a straw. (Ginny, Focus group 16/08/18)

Yeah, I mean, the thing is, with me, all the way through primary school I was taken up to physiotherapy every day, which was good, but the thing about it is that all the therapy in the world didn't actually... it kept me active, which was really good, but there was no real improvement in my strength or anything like that. (Maurice, Individual interview 27 November 2018)

Parents of disabled children spoke about the importance of their children having school and friends. For parents, the sense of belonging is intimately connected to how well they feel their child is accepted and included at school.

I think I must have cried when [child's name] got her first one [birthday invitation]... Yeah, that was definitely a huge milestone, getting your first invite (Anna, Focus group 15/10/18)

I was like, right, I'm gonna ask his mum if [child's name] wants to come over for a play date and I had this real moment of, oh my gosh, what if she says no? What if she rejects us and doesn't want him to come over for a play date? ... It just really reinforced to me how fragile that sense of belonging can be, based on the relations with the people at that time and in that space (Carey-Ann, Focus group 16/08/18)

Uneven power relations between parents and teachers was talked about as challenging parents' sense of belonging

That's another hierarchy is between an expert and a parent. Even though you had a PhD...you were always belittled and dismissed even though you probably knew more about inclusion than a lot of teachers there. They were the experts; which of course happens in education (Tony, Focus group 10/11/18)

### **Disabling work spaces**

Work spaces are another significant place for disabled people. Able-bodied assumptions are often built into workplaces. For example, there are expectations about: hours of work and inflexible working conditions; offices with standing desks; invasive questions from colleagues about equipment; and, limited understandings about impairment and disability.

I'll start a new job. Everyone has walked past me like, 'Oh! Flash equipment! Oh! Why do you have this keyboard! Oh! Why do you have this?' [participants agree] It's like, 'Fuck off!' So, you're forced to out yourself to people you don't even know (Rebecca, Focus group 16/08/18)



When I first started at the [organisation name] I met with this health and safety person who was talking about my desk set up and stuff. She started talking about standing desks [uproarious laughter] It was like, um, I don't think I'm gonna need one of those. [laughter] I looked at her face and I was like, 'sorry, that was a joke,' [uproarious laughter] but seriously, I'm not gonna need one, so don't worry. Then I was like, 'oh and I bring my own chair' and she was like, oh so awkward (Sophie, Focus group 16/08/18)

No, like even little things at work, like why are you going home early? People just, if you present as well, it's a bit trickier work spaces can be quite difficult, like I've had to quit jobs because of my health before, or go down to part-time (Laura, Individual interview 11/12/18)

Work is a place where some participants feel they are under surveillance and scrutiny. Feelings of judgement and power relations structure workplaces. Some participants use different strategies to minimise (and hide) the visibility of impairments.

But in a lot of workplaces I've been in, there's not, and again because you don't look sick; you don't look like you're in pain. People don't see you rushing to the bathroom because you're retching from pain. People don't see that, you put on your public face, in terms of hours (Laura, Individual interview 11/12/18)

## Dating and relationships

One of the topics that arose from the interviews was about sex, dating, gender and sexual identities. We note, from other research, that not many disabled people have had the chance to speak about sex and dating. The notion of 'sexy encounters' – including where and how sexual encounters do (not) take place – is important. Cafès, restaurants, bars and online dating websites are some of the places where people felt in (and) or out of place.

For women and queer participants, online spaces could be fraught and they receive numerous friend requests from men they have never met.

Online dating and stuff like that, but I find it so extremely stressful ... I don't know how to present myself online. (Esther, Focus group 16/08/18)

I've had weird [Facebook] friend request from random disabled men in Auckland who I never met before ... I'm just so glad I've been in a relationship with someone for six years and possibly getting married to them (Ginny, Focus Group 16/08/18)

People's gender and sexual identities and relationships are often questioned and this happens in a variety of social spaces. Non-disabled people's attitudes and actions impact on feelings, identity, and relationships.

As a single mum with a child with Down syndrome, I worry that people might be judging me that my relationship broke up because we had a disabled child (Carey-Ann, Family Focus Group 15/08/18)

I feel like I don't belong in a lot of queer spaces, I guess. I get them as that validation, you know, like when your sexualities more like you know who you're attracted to ... but I don't think I read as very queer ... It's sort of like with my mental health you can't see it; my physical health you can't see it because I look fine, and my sexuality you can't see it (Laura 11/12/18)

Participants acknowledged that dating and forming relationships was challenging. As illustrated below, even going to a cafe can be difficult.

Jolene: It [dating] is a very confusing space. Even non-romantically, it's a very confusing space. I find it really hard having significant relationships with people that aren't disabled. Maybe that's not true of all people that aren't disabled, but a lot of people that I feel like I would be quite close to if I wasn't disabled. There's this barrier. There's this thing in the way, because they don't know how to react.

Rebecca: Well, they don't know how to include you.

Jolene: They don't. They don't know how to include you.

Rebecca: Like hey, do you want to come out for coffee?

Jolene: Exactly.

Rebecca: Then it's like, I'd love to come out for coffee. Would it be okay if we do it at this café, because I know I can sit there, and they're like 'oh shit.'

Mere: You're too high maintenance.

Jolene: Exactly – too high maintenance. There's a lot of that (Focus Group 16/08/18)

The importance of embodied diversity – that is, acknowledging one's impairment, gender, sexuality, and so on – is vital for creating spaces of belonging when forming relationships.

Mere: The disabled community's quite varied and it's everyone else's perception maybe if they don't interact with disabled people or just have limited experience or something, is like, oh, yes, very homogenous. Totally asexual. Oh my gosh, can't have a pretty disabled person ...

Rebecca: I like that you bring up asexual, because God forbid we'd want to have girlfriends or boyfriends or be sexually active or...

Jolene: Queer (Focus Group 16/08/18)

We're disabled people, but we're also other things as well. We're queer, we're female, we're non-binary, we're all these different things and they are all connected. We're a holistic human being who has different needs (Rebecca, Focus Group 16/08/18)

Understanding disability, gender and sexuality as interwoven is vital in order for feelings of belonging.

## Summary

The research has shown that the notion of belonging can build upon conversations around disability, community and inclusion.

1. Disability spaces can give people opportunities to identify common experiences, learn new ways of talking about and understanding disability, and share useful information that helped in navigating the experience of disability.
2. The way in which non-disabled people react towards disabled people impacts upon disabled people's sense of belonging.
3. Schools and work places are significant spaces in the lives of disabled people and families. Able-bodied assumptions make it difficult for disabled people and families to feel 'in place'.
4. Where and how sexual encounters do and do not take place – is important. People's embodiment – impairment type, gender, sexuality, and ethnicity – impacts upon spaces of belonging when forming relationships.

This project has also demonstrated the need for more disability-led and owned knowledge, communities and research.

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