

Belonging and exclusion in the lives of young people with intellectual disability in small town communities

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Abstract

In recent policies, it is assumed that communities welcome the inclusion of young people with intellectual disability. However, little is known about perspectives of young people themselves. This article reports on research that sought to address this gap. Young people with intellectual disability living in three Australian small town communities participated in pictorial mapping and photo-rich methods to explore belonging and exclusion and links between these. Young people's feelings of comfort and safety with local spaces and people were important for their sense of belonging. Emplaced relationships with family and some friends were key to strong belonging, as were positive attachments to disability support workers and spaces. Social exclusion, either from particular places or more generally, was keenly felt. Young people's confidence, willingness to enter social spaces and relationships were magnified by ways that systems responded to their impairment, at worst fracturing their sense of feeling welcome and included.

Keywords

belonging, exclusion, intellectual disability, photo research, young people



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Introduction

In Australia, as elsewhere, policy concerning young people with disabilities is currently undergoing a significant shift from welfare models towards more person-centred approaches (Fawcett and Plath, 2014). This has resulted in substantial investment in individualized support which aims to enhance community inclusion and relationships. While broadly welcomed, concerns persist about the capacity of service systems to sustain nuanced support over time to people with complex needs (Authors, 2015; Stalker et al., 2015). Alongside this, in recent policies, assumptions are made that wider communities welcome and encourage this shift towards community inclusion.

In this context, the ideas, hopes and concerns of children and young people affected by these trends are little heard – particularly those who have voices more difficult to hear. The shifting policy context offers both new opportunities and changing risks for these young people. In this article, we draw on accounts gathered in recent research to discuss how connections to place, space and people influenced a felt sense of belonging and exclusion for young people with intellectual disability, and from this, implications for building more responsive social policy.

Background

Previous research has highlighted that the concepts of connectedness and belonging are central to understanding social inclusion and exclusion (Nagel, 2011; Warr, 2015). Although these are closely related concepts, the distinctions are also important. Connectedness can be conceived as the number and quality of connections an individual has with people and places (Franklin, 2014). These contacts may be positive, negative, neutral or ambivalent.

Belonging involves relationships with people and places that mainly entail positive and long-term attachment. Described as space which is symbolic of ‘familiarity, comfort and security, and emotional attachment’ (Antonsich, 2010: 645), belonging is acquired over time and shared history. It is both a place to feel at home, and the experience of the political and social relations that make this possible. Many people with disabilities often spend much time in segregated settings, such as ‘special’ schools and day centres. Hall (2010, 2013) argues that in understanding belonging and connectedness for people with disabilities, it is vital to appreciate the nuanced ways in which they navigate relationships with others (known and unknown to them), in both ‘mainstream’ environments and segregated settings.

Facilitators and constraints for feeling a sense of belonging

Young people with disabilities themselves report that being accepted by peers, feeling capable and valued, and supportive relationships with adults are key determinants of their belonging and connectedness (Avramidis, 2010; Foley et al., 2012). Established patterns often change significantly during the transition from adolescence to adulthood and young people with intellectual disability have to renegotiate these relational determinants, something particularly challenging when other community members may disregard their strengths (Diez, 2010; Prince and Hadwin, 2013).

Like other young people, friends are potentially particularly important facilitators of a sense of belonging and connectedness for young people with disabilities, but can also be a considerable source of tension (Flynn and Russell, 2005; Salmon, 2013). Friendships for young people with intellectual disabilities can frequently be difficult to develop, and the extent and depth of their friendships may be limited or damaged by intolerance in peers and others (Morrison and Burgman,

2009). In addition, young people with intellectual disabilities may be particular targets for bullying (Prince and Hadwin, 2013), which poses a strong threat to feeling secure in both friendships and community (MacArthur, 2013).

The impact of geography on belonging is also important. Restricted access to leisure and commercial activities, or to support services, on account of various age thresholds can limit young people's movement and access (Authors, 2009). The availability of activities and support services may also vary greatly depending upon where young people live on the rural–urban spectrum (Leyshon, 2008). In small country towns, like those where participants in this study lived, people are close to large open spaces, but services and public transport are usually limited in range and scale, or missing altogether. On the other hand, relationships among community members tend to be close (Pretty et al., 2002), and people can engage in locally generated sporting and cultural activities (Ouellette-Kuntz, 2012).

A theoretical frame for belonging

In this research, we have drawn on key understandings from social geography, the interdisciplinary field of childhood studies and the social relational model of disability to provide a distinctive lens through which to explore the significance of some of these contexts for young people.

Social geography was used to frame our understanding of connectedness and belonging by exploring how notions of space and place are intimately involved with relationships as young people with intellectual disability experience them (Hall, 2010; Imrie and Edwards, 2007; Pain, 2004). Places are fundamental for people in expressing a sense of belonging and a locus for identity (Imrie and Edwards, 2007).

The geography of disability has generated a considerable body of research over the last few decades. A steadily increasing focus on socio-spatial and relational geographies of children's lives has progressed theory and methodology around embodiment (Holt, 2015), ableism (Pyer et al., 2010) and participation as both construct and activity (Horton et al., 2008). Intersections between childhood, youth and disability are increasingly problematized and coming into critical interaction with core concerns of social geography, such as belonging and connectedness (Hopkins, 2010). However, despite this, people with intellectual disability have primarily remained at the periphery of geographic enquiry (Holt, 2015; Power, 2010).

Childhood studies theory, with its emphasis on the social construction of childhood, along with advocacy around children's rights, participation, agency and competence (Thomas, 2007; Tisdall, 2012), is the second theoretical lens. It stimulates conceptions of young people with disability which are informed by age and life stage, rights and capability, and a 'child-first' rather than impairment-framed approach. More recently, the interests of children with disability have been brought into stronger focus in some childhood studies scholarship, particularly in contesting normative constructs of agency and contribution (Valentine, 2009), and stressing the intersectional nature of disability (Konstantoni and Emejulu, 2017). Curran and Runswick-Cole (2014, 2017) have led the development of disabled children's childhood studies, with a focus on 'enabling disabled children to step outside the "normative shadows" that so often cloud discussions of their lives' (2014: 1618).

The third lens in our theoretical frame is the social relational model of disability. This attributes exclusion to social discrimination, and a failure in the provision of environments that could better enable inclusion (Thomas, 2004). Increasingly, influential perspectives of theorists such as Danermark and Gellerstedt (2004) and Shakespeare (2014) about the relational nature of disability

are pushing debates beyond a social/medical model binary and into more nuanced territory about the complex factors at play in understanding disability, impairment and exclusion and their multiple interrelationships.

Similarly, young people with intellectual disability are typically characterized by others in terms of their impairment, while their relationships, too, are often seen in terms of dependency on others. Taken together, childhood studies and social relational approaches to disability encourage acknowledgement of agency and ways that young people give as well as receive in relationships of interdependence (Power, 2010). This points towards the importance of understanding how both reliance on others, and contributions to others, affect young people's lived experiences of inclusion and exclusion.

This conceptual linking responded to the evident need to improve understanding of the ways in which young people develop meaningful and fulfilling relational connections in a range of places and spaces, which first became clear through advice young people provided to us in advisory meetings about our wider research agenda.

Research aims, design and ethics

The aim of this research was to investigate the lived experiences of belonging and felt exclusion for young people with intellectual disability living in regional (small town) communities. It was funded under a national competitive grants scheme which aimed to develop new knowledge to support disability policy in Australia.

This article focuses on the findings from the project about how the young people's experiences of connections to place, space and people influenced their felt sense of belonging and exclusion, and from this, implications for developing social policy which is more responsive to their priorities and lived experience.

Research design

The research design for this study reflects its underlying social constructionist interests. The study took as a starting point the idea that participatory research involving young people with disability needed to be co-designed and collaborative. To this end, mixed methods were developed that supported young people's contribution at each phase (see discussion below). The data reported here are drawn from the qualitative phase which took place in three country towns, with populations of around 30,000, each located in a different Australian state. Sites were selected based on comparable size of towns, consultation with each community and negotiation with disability service providers who were willing to support young people's involvement in the project.

Participants

Young people were recruited voluntarily through disability support service programmes for young people with intellectual disability. Five staff and managers from these programmes were also interviewed as part of the research.

Thirty young people aged 12–25 years participated in repeat interviews and in a photo research project, across three core groups. One group were aged 12–16 years, and two groups were aged 18–24. Across the 30 young people, a diverse range of capabilities and interests was reflected. A few of the young people were very capable, for example, of travelling independently around their town and meeting up with friends on the weekend without any assistance. Most needed assistance from

either family or staff with activities outside of the routine in their lives. For example, many people travelled to and from town on buses independently but needed assistance if travelling somewhere new or different to their usual route. Seven people needed assistance with most activities of daily living, including communication, preparing and eating meals and moving around in their local area. Four of these people had very significant support needs (e.g. they had multiple impairments and used symbolic communication with assistance).

Most of the young people lived in their family home, with at least one parent and often with siblings. Four lived in supported housing (group homes) with other people with disability, with staff support. Most lived in a township, with three living in small outlying villages and four on farms.

Methods

Research questions for the project focused on the nature and extent of young people's connections to place, space and people within their communities; what helps and hinders in facilitating a sense of belonging; the effects of living in a small town or rural area; and how current service approaches might better support inclusion. The broad research questions were established at the project funding stage, but in order to make both the direct questions and the interview processes accessible to as wide a range of young people as possible, the team developed multiple methods and the fieldworker met several times with young people and their supporters over approximately 6 months.

A subgroup of young people from the project was also involved throughout the study in development of the methods, research design and resources and in writing easy read project reports. Some people were consultants from the outset, and some young people were recruited after participating in the research, based on their interest in further involvement. We were able to include a diverse range of people, but our original plan to set up a peer-supported group to advise the research team was not possible due to distance and complexity in the design. Our secondary strategy involved people in as much as possible across the project life, including method and resource design, analysis advice and knowledge transfer. This did, however, limit the involvement of young people in guiding the initial project design and peer-supported advice.

Research activities were designed to build a multilayered and relational understanding of belonging and exclusion with a core group of young people and promote the results in their local communities. This approach built from prior participatory (Hall, 2010) and photovoice (Jurkowski and Ferguson 2008) research with people with disabilities. The methods are described briefly below.

Mapping sites and relationships with young people

Pictorial mapping was an integral part of initial individual interviews with the young people to help them describe the people and places important to them (Figure 1). This method proved especially useful for the young people who found it difficult to express themselves in detail using words alone (Christensen et al., 2015). Twenty-eight participants (two were away) engaged in this process of mapping, using their depictions to help describe the meaning and significance of their relationships. They were also asked in this interview for their thoughts more broadly on what it means to them to belong and be connected to others. Twelve of the 28 were not able to respond directly

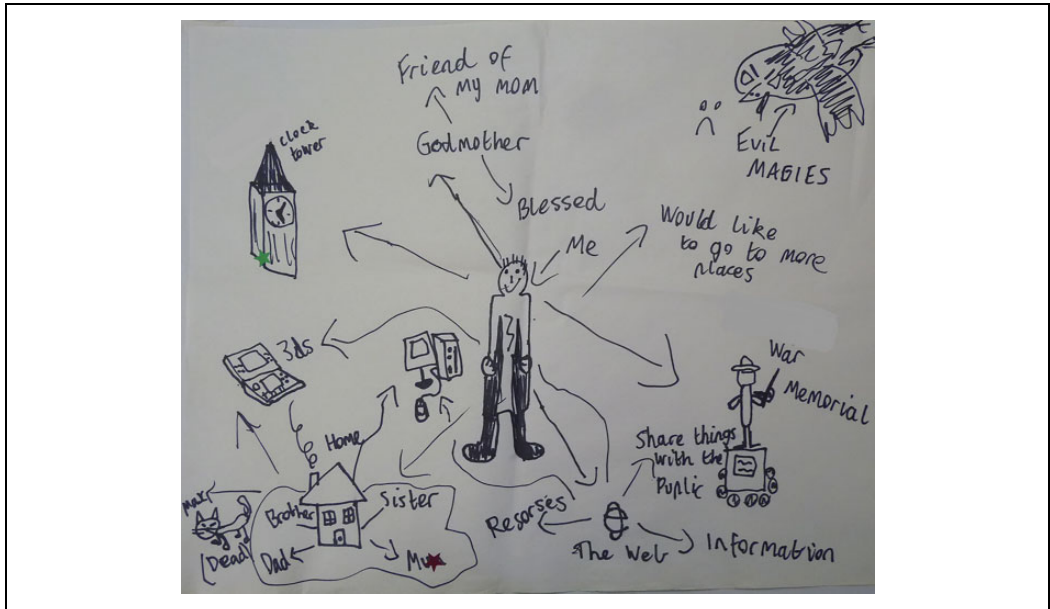


Figure 1. Angus' map.

because the question was too abstract. This highlighted the value of obtaining their views by other means.

People with high support needs contributed with support from communication partners, who assisted by providing advice on the young person's communication skills and preferences, interpreting communication, making the researcher's language more concrete and relevant with examples for the young person where needed (including with symbolic communication) and explaining the significance of relationships in the young person's life. These were people who knew the young person well – service providers, family members and advocates.

The contributions of each participant were brought forward from their individual mapping interviews into workshops for group discussion, confirmation and addition. These workshops also included group activities and games to introduce participants (24) to the photo research aspect of the study.

Photographic research projects

Photovoice is an accessible, visually rich research method that supports the involvement of participants as co-researchers in the design of the research, photographic data collection, analysis of their photographic data and dissemination of results through public exhibition of selected images (Jurkowski and Ferguson, 2008). After the first interview, young people were provided with pictorial resource sheets covering topics, such as 'my town', 'a day in my life' and 'how do people see me' and asked to photograph people and places that mattered to them. With the support of facilitators in each local service, participants took photos for 8–14 weeks and uploaded the photos they wished to share, along with captions, to the photo sharing website, Flickr. The album was shared with the research team but not accessible to the public. The choice of photos to upload

rested with the young person, but the fact that adult facilitators were with them may have influenced the images they chose to share.

Second interviews were conducted with the 30 young people during which they were supported to explore their perspectives, using their photography and self-developed captions as the stimulus to tell a story about what helped them to feel ‘a sense of belonging’. Through this process, each person analysed their own work, ranking the importance of their photos, effectively coding them into categories and themes (Nind and Vinha, 2014). They then selected key photos they wished to contribute to an exhibition and developed an explanatory statement about the story their photos told.

All participants engaged in this analysis activity, including young people with significant support needs. For example, Simon was an enthusiastic and artistic photographer in the project. He speaks little, and his social relationships are shaped by significant autism. Simon progressively selected his preferred images by choosing from sets of three related photos he had taken (centred on cooking, art and gardening). Images were offered more than once in different groupings to test his preferences and he reliably chose the same images, firmly pushing away the ones he did not like.

Public exhibitions

In order that the project gave wider recognition to those who took part, each project concluded with a public exhibition of the young people’s images. Held in high-profile locations, all three were well attended. At the suggestion of the young people, a website was created, partly so they could share their own photos and also so they could see the work produced at other sites.¹

Data analysis

Interviews were digitally recorded and later transcribed (with appropriate consent). Maps were photographed, and all photos taken by young people and their captions were downloaded and securely stored. All data from interviews and the photographic and mapping material were coded for shared meaning using NVivo software (QSR NVIVO 10). Codes were categorized into themes according to the emergent findings about key concepts as coding proceeded. Secondary analysis created new thematic categories about belonging and connection which were tested by cross-analysing intersections and interactions between these ‘higher level’ thematic categories. For example, the category of ‘being known’ emerged from a combination of the themes of feeling comfortable/secure, friendship as a facilitator of inclusion, supportive relationships with paid workers and being respected. Categories of ideas about belonging and exclusion were generated and grouped as the foundation for our findings (Richards, 2009).²

Key themes clustered within four domains and are presented in the next sections.

Limitations

The geography of Australia and the resources available for the research meant that the methods were conducted in part from a distance – young people completed several weeks of the photography either independently or with support from their service providers and research resource sheets. While the methods and process were inclusive, including parts of the design, analysis and dissemination, the idea for the research was developed by academic researchers before being taken to people with disability for involvement.

Ethics

Given the sensitive nature of this research, close attention was given to the ethical dimensions of the study. Ethics approval for the study was provided by Southern Cross University Human Research Ethics Committee. Beyond this, the team adopted an ethical stance of ongoing reflexive engagement, creating a hermeneutic ethical environment and close attention to the various issues that emerged ‘in-situ’ (Graham et al. 2013; Guillemin and Gilliam, 2004).

For example, consent and assent to both participating in the project and to the use of images required adapted materials, along with iterative conversations with young people. At the outset of the project, each person was provided with consent material in easy read and pictorial formats, and the researchers also worked through this in person with them. At each meeting, consent was refreshed. At key stages (such as deciding to share images), new easy read and pictorial information was shared and worked through together. This scaffolded approach to consent worked well to help young people understand what they were agreeing to. Where young people preferred or when we were unsure about the degree to which they understood the implications of their decision, parents and guardians countersigned.

The research team observed closely how participants were engaging with the research process, giving particularly close attention and responding to any non-verbal and verbal cues that young people with higher support needs might wish to withdraw their consent or assent. For example, it was jointly decided that one young man withdraw from the study after it became clear that he did not enjoy being involved in the photography workshops or activities and found the group activities overwhelming and upsetting.

Images reproduced in any context (including this article) are with explicit permission from the young people. All names in the article are pseudonyms.

Results

How young people conceived of belonging and exclusion

The findings are underpinned by young people’s own conceptions of belonging, and not-belonging. Several young people identified that being recognized, valued and welcomed critical for a sense of belonging. When young people felt there was congruence between how they saw themselves and the way that other people related to them, they felt valued and understood – known in a positive way. Extended family were important contributors to these core relationships, particularly grandparents. For many, friends were important in supporting feelings of well-being, and also promoting a sense of status. Young people felt valued in their relationships with support workers when they demonstrated respect – this was embodied through support workers’ voice and actions, evidence of strengths-based support approaches and in them knowing when to step in, and to step back. The importance of being recognized was well articulated by Megan:

Probably just feeling like I’m appreciated and people actually see that I’m there. Rather than just seeing an invisible person walking past, like they usually do.

This sense of acceptance in relationships was of fundamental importance to several young people, but not always felt in personal relationships or wider social contexts. Many young people identified a sense of safety – both physical and emotional – as significant to them in underpinning a sense of belonging. For some, it was important not to stand out, and to be able to fit in, as Frankie noted:

It's not fun to feel you don't belong. Cause it's like everyone's over here and you're all the way over here with your arms crossed, and it's just like 'why don't I belong?' cause you feel really sad. And everybody's all smiling and laughing without you and you're all the way over there crying.

In both individual and group conversations with the young people, a strong theme was feeling comfortable in relationships, social situations and physically in places. Feeling comfortable provided confidence to enter, remain and explore places; while discomfort could stop young people attending at all or prompt departure, resulting in self-exclusion. These two contrasting quotes illustrate this:

For me, what it means to feel like I belong is I can go anywhere and just feel comfortable. (Zac)

If you don't feel comfortable, you just feel like leaving. (Nikola)

Emplaced belonging was based on long-term continuity for some people. Young people's maps and photos of places they felt they belonged to included familiar and prominent structures in the built environment. The presence of family made other places seem theirs. Certain people noted how formal membership and familiarity over a period of time contributed to their identification with, for example, a football club or a disability organization.

A few people emphasized the importance of mutuality to feel connected to others. For example, one person talked about their determination to develop relationships and another stated that helpfulness to others facilitated acceptance. The importance of mutual respect in relationships and taking time to develop a fuller knowledge of each other were both mentioned as qualities in relationships that young people valued.

The next part of the findings discusses how young people articulated their identities, and the ways in which their relationships were enacted in places and spaces: in accessible terms, *who I am, people I know, places I go and things I do*.

Who I am

Almost all young people in this study mentioned sites away from home, centre or school where they pursued favourite sports or other active interests like dancing and music. Connected to these sorts of leisure activities, several young people pointed to characteristics and interests they possessed, which contributed to a more complex identity and confidence to feel included. This was evident in their frequent selection of photos of themselves in domestic or public places where they were engaged in activities they were good at or proud of, with captions centring on self-identified qualities such as being caring about others, artistic, athletic, a good worker or being skilled at activities like cooking or dancing. People who described fewer relationships had more photos demonstrating their capabilities and a high number of 'I can' or 'I do' statements describing their images.

While most of the photos that young people contributed showed places that might be used by any young person, some photos also showed specialist sites mediated by medical responses to their impairments. Gemma, for instance, included photos about diet, exercise and therapies she and her family completed daily to manage her health conditions. Wayne showed a mobile trolley piled with the medical supplies needed to support him through the day and pictures of inaccessible stairs and a lift. The people who discussed impairment presented it mostly as a barrier to social inclusion. Jums, for example, talked about the way she felt about assistive equipment:

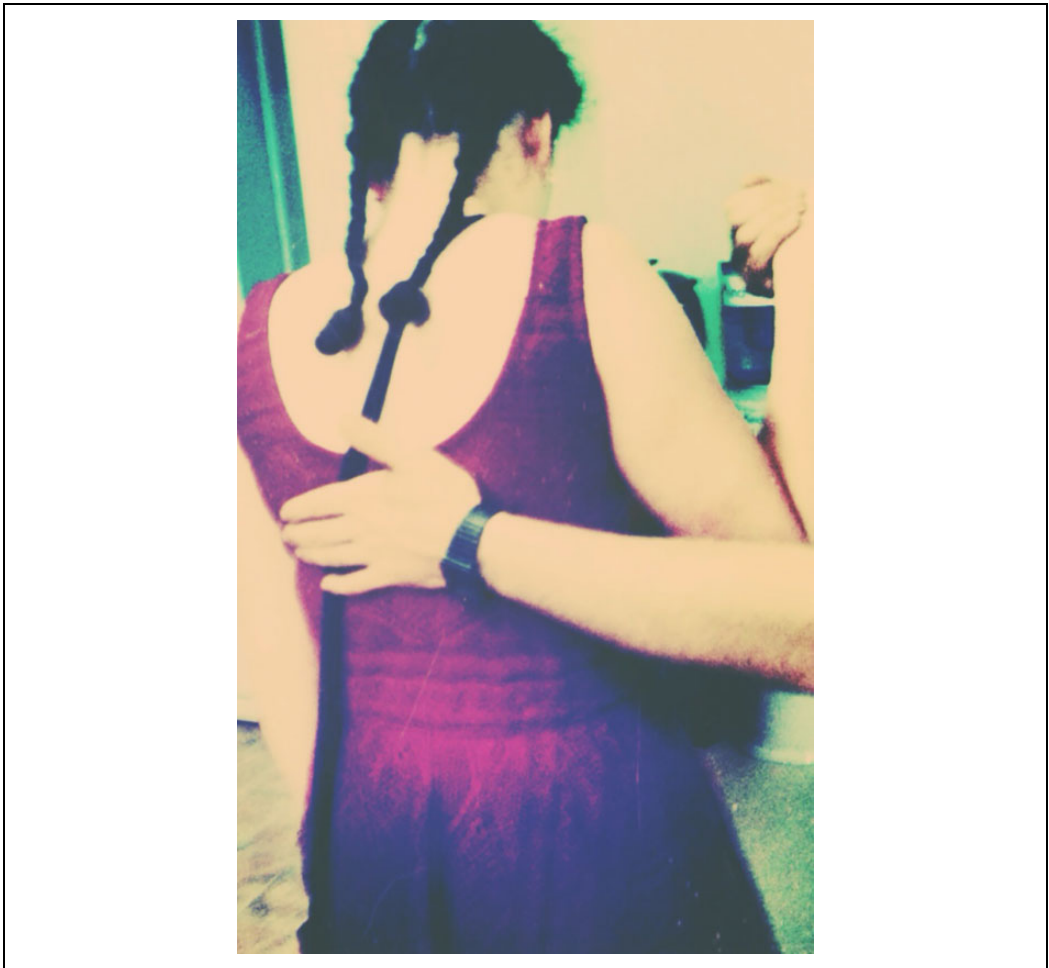


Figure 2. 'Unwanted support' by Jums.

I don't like the wheelchair that much, 'cause I don't like being too different from everyone, so I would rather be walking or something... I just feel like the wheelchair makes me too different.

Several young people struggled with the level of agency they had over choices and decisions, either questioning or disputing the level of self-determination they had. Some documented the difficulty and tension in accepting care that they did not want, particularly at a life stage typically associated with expectations of increasing independence. Jums' photo (Figure 2) eloquently describes the tension of needing physical assistance in her daily life, but not wanting it.

Some differences in the photography and dialogues also related to gender. Young women and girls talked more about relationships and boyfriends and seemed to invest more interest and energy in this topic. Their self-identifications were also more affective, including reflections such as '*I am kind*', '*I am a nice person*' and '*I'm soft-hearted, sociable and easy-going*'. Some of their photos were about having a good time in glamorized ways – at a ball, the beach, at a disco and captions

such as, *'heey, sexy ladies!'* underlined this. Men and boys focused more on the ways they viewed their capabilities, saying things like *'I am confident'*, *'I am a professional worker'* and *'I'm a sportsman'*.

People I know

In this article, we highlight two relationships that were centrally important to the young people in this study – friendships, and relationships with support workers. Young people also identified close connection with parents and other family members. Many also discussed wider social relationships which formed looser social networks of neighbours, family friends and shopkeepers in their local areas.

Most young people rated friendship as very important and included many photos of friends in diverse locations in the photography phase of the research. For the one-third of young people with more complicated family relations, support received from friends was very important. The friendship networks of most participants were largely confined to fellow service users and former school friends and their emplaced relationships reflected this. People under 18 were also less engaged with disability services, and their friendships were mainly through their families and school. People with lower support needs had developed more organic friendships which had grown more organically, based on activities which extended beyond the disability service, and more strongly on their preferences.

The smaller group of young people with higher support needs described few friends and little social and emotional connection beyond family and professionals, spending little time beyond their homes and disability services settings. While not able to verbally express this, they showed this through the selection of images in their photo research. Three people with high support needs selected photos of people they seemed to like in their photo sets, based on their responses to viewing the photos, and their reactions to them, observed by the researchers in daily life. In the interviews, people with higher support needs were more likely to be prompted by support workers to describe other people who used the service as friends. They spent a lot of time together, and certainly knew each other well. For some, friendship was viewed through a programmatic lens. For example, when asked *'What do you like to do with your friends?'* Jarred's response was couched through service activities, despite having a rich and varied life:

Sometimes we go for shopping on Monday morning. But we'll split up the group, and on Monday morning make a best plan. We're doing cooking on Monday morning and we're doing hilarious hats on Monday afternoon. And we're doing Magic Monday as well.

Several young people talked, however, about friendship being circumscribed, hard to navigate and at times unreliable. Implicitly or explicitly, these forms of felt social exclusion were related to others' negative or indifferent perceptions of their impairment. For instance, Ellyse felt close to someone she played sport with but was hurt that this person did not invite her to parties and gatherings at her house. Harry said he was not as popular at the local (mainstream) school he attended, compared to his former special school. Discussing his photo of the bowling alley, Derrick talked about his difficulty in bridging the divide between presence and inclusion:

What do you think about [your picture of] the ten pin bowling alley?

I love it.

Why do you love it?



Figure 3. 'Jamming' by Luke.

Because cool people get all the strikes. That's why I try make lots of friends.

Is it a place where you can go and make friends?

I just say 'hi'. I don't play in a team but I do play by myself.

Would you like to be in a team?

One day.

Relationships with disability support workers also formed a distinctive category, along with other service providers including health workers and teachers who also featured in young people's interviews. Positive relationships with particular support workers mattered for some young people's feelings about being known, valued and confident in engaging in their community. Zac included a photo of the noticeboard and a list of names of young people and workers, which records changes to the daily roster allocating workers to clients. He said:

Yeah, it's a bit of a run-around thing. As soon as you walk in, it's like 'who am I with?', going to the board... Yeah, yeah, it changes how I'm feeling about the day.

Similar comments from other young people indicated that some relationships were to them viewed as supportive and enabling. For example, support from some workers facilitated young people's engagement with people and places outside of the services in which they spent a lot of time, and many people enjoyed this. At times, however, people were irritated when support workers made little effort and took them to the same places repeatedly, instead of finding more imaginative or creative activities. For young people with high support needs, contacts with professionals were more prominent in their lives than friends or occasionally family members. For example, in Figure 3, Luke shared the importance to him of co-writing and playing music with his regular support worker, reflecting that 'he's very friendly, and he helps me on my music career'.

Places I go

In social geography, places are those sites which are imbued with personal meaning, often because of the relationships and/or history built there. Most of the sites that young people identified as important were mediated either through the relationships or activities they engaged in there. Young people described many connections to places through the multiple methods in this research. Mostly, these places were located in or nearby their home town. Of most significance to young people were home, disability services, school and the virtual world(s).

Usually positive, or even ambivalent, family relations meant the comfort of home provided most people with a stable base with loving relationships. However, one-third of young people described family experiences of loss and grief, abuse or interpersonal trauma, which affected their happiness and attitude to home. Sensitivity about negative feelings in the interviews meant it was often conveyed obliquely, as this excerpt from Bella's interview illustrates:

Is home an important place for you?

It depends on what's happened.

For some, being well known in their small neighbourhood was supportive, whereas for others it was stifling. All seven young people who lived out of town valued living rurally, for example, on account of the sense of freedom. The remainder mostly felt a sense of belonging in their town, because of its familiarity. Ellyse, for example, said she belonged in her town, because she had lived there all her life, and knew her way around. However, some others noted the limitations of regional living, pointing out the smaller range of activities and entertainment and 'good shopping' for young people, compared to large cities.

Things I do

Many of the young people visited places either with friends or to see them. Several young people related how they valued public buildings, both for symbolizing a sense of emplaced belonging and as venues for socializing. For example, shopping was a frequently mentioned activity, with browsing and meeting friends described as equally important as purchasing. This mostly took place in the local town centres, but a few people extended their spheres of activity by going to the closest big city 2–3 hour's drive away.

For the small group who moved about independently, town streets were popular sites to gather with friends, as were transport hubs (bus and train stations). Having positive peer relationships usually entailed interaction with diverse places, including friend's homes, shops and leisure facilities. On the other hand, several people said they restricted themselves to certain pubs or clubs

they knew to be safe, while others only went to friends' homes at night because they thought public places were unsafe. Some young people talked about only using certain routes and places when with friends, since being alone could be risky. Not unexpectedly, a few young people were attracted to risks and dangers rather than deterred by them, such as spending time on the streets at night, or not using adaptive equipment.

Limited public transport meant that young people were primarily reliant for travel on taxis, walking or lifts by their families, which could restrict their access to desired places in timing or frequency, or altogether. Many people made a distinction between their local neighbourhood and what they called 'town', referring to the town centre. Some were frustrated they could not visit the latter more often. For some who lived out of town (whether meaning the centre or the whole settlement), getting their driving licence was a key goal, and one in reach for around a quarter of people in the research. People with higher support needs went to fewer discrete places, and they were primarily reliant on family or staff members for transport.

Not-belonging

One-third of the participants described parts of their lives which were difficult emotionally and at times abusive. This included being removed from parental care, emotional and physical family conflict, being let down, not feeling able to trust family members and feeling judged about core parts of their identity. This had a significant impact, influencing other domains in their lives and parts of their identities. For some, home was not an easy place to be, because of the level of conflict, loneliness or loss and grief. Experiences of violence and abuse were raised by five young people, both as victims and instigators of violence. Further, a number of young people lacked support to cope with serious harm. The impact of this was evident, leaving them fearful, angry and anxious. People with high support needs were not able to talk about this more abstract topic and it is likely that they have experienced negative aspects to their relationships too. One person included the words of their tattoo as a caption for a photo, as they described their experiences and resilience. They also highlight loss and grief:

I don't trust many people

I forgive but don't forget

I want to be free

Learning from my pain

What doesn't kill you makes you stronger

Many young people spoke openly about feeling lonely, and their desire to have more or deeper friendships. Less direct similar sentiments were also present in the narratives of some others, who spoke about feeling isolated due to where they lived, wanting to join in but not feeling confident and undertaking activities with family instead of with friends. The few young people who had few or no friendships also tended to have fewer places where they felt comfortable and accepted. These were mostly young people who thought others identified them primarily by their disability or who felt uncomfortable or vulnerable to prejudice outside home and disability specific settings. The service context of the research may also mask some loneliness or absence of friends elsewhere, as they referred to peers in the service as friends.

Feeling uncomfortable and unwelcome in places was noted by several young people as likely to result in them excluding themselves, either because they were unsure of social rules, fearful or uncertain. Lack of acceptance and exclusion was particularly painful for several young people, as Frankie said:

If you feel left out, you don't really feel like you belong. And it's really – it really hurts you . . . Cause a lot of the time I know what it's like to feel not belonged. Because I feel that way a lot.

As can be seen above, the primary concerns of young people in this study were about finding and keeping friends, having a sense of agency, and feeling and being safe. The next section of the article discusses the implications of these priorities.

Discussion

The experiences of connectedness, belonging and exclusion of this group of young people have much in common with young people of similar ages without disability (Warr, 2015). In addition, particularly for those with high support needs, there were distinctive aspects. While many young people had a diverse range of relationships, some spent much of their time in disability specific sites and with other people with disability and professionals for socializing, as well as for support related to disability and for education (similar to that related by Hall, 2010). A few had mobility as well as intellectual disabilities, and encountered geographical barriers of access, and highlighted specific additional accessibility obstacles.

The practical barriers to participation were described in several ways similar to those experienced by any young person living in a small town or rural area, such as distance from leisure venues and limited public transport. For others, though, exclusion from places and activities was due to discriminatory attitudes and behaviour by others. They keenly felt this social exclusion and it impacted their confidence, willingness to enter social spaces and relationships. Actual or feared experiences of negativity or harm by others led some people to exclude themselves. Others, with greater confidence or support, exercised their agency to overcome anxieties and risks (Salmon, 2013).

Several factors were evident that promoted or impeded inclusion for young people, individually and collectively. Some of these factors were consistent with, or built on earlier research. Young people highlighted the importance of feeling comfortable and accepted in order to gain a sense of belonging (Hall, 2010). Having a secure sense of place facilitated belonging, and both physical places and online spaces mattered to many young people. Their sense of place was primarily local, in the places they went often and found comfortable and familiar (Pretty et al., 2002; Power, 2010). Accessibility, both through transport and in moving around the local community enabled them to be in places in their towns and enact relationships. Some young people spoke appreciatively of support from their family, friends and support workers getting to places where they could pursue well-loved activities, with some emphasizing the reciprocity in the relationships (Foley et al., 2012).

The research highlighted the importance of attention to identity and recognition (Authors, 2010). Receiving positive or negative responses from others was crucial in how young people felt able to engage (or not) with a wide range of people and settings. They felt that exclusionary attitudes by others were commonly based on identifying them in terms of their impairment and perceived limitations. Yet, intellectual disability was usually only one aspect of young people's

identity and far from a dominant one. Their comments showed how their characteristics, skills and interests shaped social inclusion in multifaceted ways.

The methods used in the project were reported by young people who participated, and by those in the subgroup who advised on the methods, to be generally positive. The research approach provided most of the young people with a supported process in which they had a choice of multiple accessible methods to express what was important in their lives. It mattered to many that we demonstrated we had learned from their experience and knowledge and acknowledged this in front of their families and workers. However, there were certainly limitations. Consent to all or part of the project was difficult to refuse in practice for the small number who wished to, in face of parents and providers who thought it would be 'good for you'. Developing and sustaining a balance between needed support and unwanted direction in relationships with support workers in the project was observed as a struggle for some young people, and also raised by young people and support workers as both a tension and learning from the project. The complexities of distance precluded an emplaced co-design group with young people.

More broadly, the barriers to belonging for young people were magnified by the ways that wider community networks and social systems responded to young people's impairment. Together, these system emphases both inadequately supported young people and led to a lukewarm welcome in wider communities. Without a strong and skilled programme of network widening and friendship building from school onwards, for example, neither young people nor their support workers were well equipped to build the community relationships called for in major policy initiatives. Community presence may be misperceived as a sense of belonging (Holt 2015; Power, 2010).

This research highlights the need to look to the priorities of young people for opportunities to build belonging and inclusion at interpersonal, policy and community levels. Being known and valued is central to a secure sense of belonging and personal identity for most young people. For these young people, recognizing their capacity and agency was a critical pathway into building this. A focus on practical skill development is needed for young people and the workers who support them, especially around relational skills for building friendships. Acknowledging the impact of loss, opening silences about loneliness and discomforts through professionally supporting young people, training staff and building community responses are measures which would build on young people's priorities for belonging and inclusion in ways currently unaddressed. Finally, the significance of place as a foundational site for relationships needs to be acknowledged – young people avoid going where they feel unwelcome or unsafe.

Conclusion

This article has drawn on multimethod participatory research to further understand the perspectives of young people with intellectual disabilities about the places and people who matter to them, as well as barriers to belonging. Many interacted with a diverse range of people and places, where they felt comfortable and respected. This reflected the exercise of agency by the young people within a context of support by family, friends and professionals to engage in activities usual at their life stage. Many expressed multiple identities and a sense of positive recognition. However, a notable minority of young people and of situations indicated their exclusion from community social life, sites and relationships. A vicious circle developed for some young people where isolation and loneliness inhibited their confidence to approach or stay in settings they found intimidating. Together, these factors mitigated against some young people feeling warmly welcomed in their local communities.

Such findings highlight the ways that multiple and intersecting social systems focus on impairment rather than relationships, capability and individuality. The findings also point to the importance of developing policies and practice that take a fine-grained approach to building support around young people, responding to their preferences and priorities, building in safeguards, foregrounding the need to facilitate relational agency with and for young people and those who support them and activating community at wider levels to not only receive, but to welcome diverse young people. This is particularly important for young people living in small towns and rural areas, where choice in support may be very limited, especially as aspirational horizons expand as young people approach adulthood.

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Notes

1. Link to website to be provided after anonymous reviewing completed.
2. The data set arising from the research can be viewed at https://epubs.scu.edu.au/data_collections/6/.

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