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# In the picture: understanding belonging and connection for young people with cognitive disability in regional communities through photo-rich research: final report - summary

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# in the picture

Understanding belonging and connection for  
young people with cognitive disability in regional  
communities through photo-rich research

AUGUST 2014 - FINAL REPORT



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With contributions from Malcolm Hill,  
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## SUMMARY

Feeling like you belong and that you are connected to people and places is fundamental to young people's identity. For young people with cognitive disability who live in regional Australia, very little is known about what helps and what hinders belonging and connection in their communities.

This research addressed this gap in our knowledge by working collaboratively with young people. We asked young people what helped them to feel like they belong and they are connected, and what makes it hard. We supported them to describe their connections, and to explore the facilitators and barriers to belonging and connection, including the impact of living in a regional community. The views and experience of young people about participating in research were also gathered through the research process.

This report explains how the project was run, and what we learned about belonging and connection from working with the young people. A companion easy English report provides summary information.

## RESEARCH APPROACH AND METHODS

The project applied ideas from social geography to explore understandings of belonging and connection with young people with cognitive disability. Using these methods meant recognising the places, people and spaces which jointly influenced young people's understanding of themselves and their feelings about belonging and connection.

Thirty young people with cognitive disability took part in participatory research in three regional towns in NSW, Victoria and Queensland. They researched belonging and connection using a range of accessible research methods including photographic projects, pictorial mapping and interviews.

All thirty co-researchers contributed substantially to the project, through interviews, workshops, analysing their photographic data, and in public exhibitions of their work.

An easy English online survey was also completed by twenty six young people with cognitive disability in additional regional communities.

The ethics of the research needed careful consideration and planning, including building in staged consent at multiple points and strategies for maintaining confidentiality in small communities.



► *Jamming together.*  
By Luke

## RESULTS

### Dimensions of belonging and connection

The research identified what belonging and connection means with some of the young people in interviews and workshops at the start of the research.

Young people's knowledge was confirmed by exploring their original definitions through the photographic methods which also included young people with higher support needs. The ways in which young people in this research understood belonging and connection resonated with established conceptualisations, but with some important distinctions.

#### To feel like you belong:

- You feel comfortable with places and people
- You feel safe with places and people
- You feel that people see and appreciate your capabilities
- You have a sense of place
- You feel included and accepted
- You feel like you fit in
- You feel valued and respected by others
- You have fun in places and with people important to you

#### To feel connected:

- You feel supported, and that you offer support to others
- You feel known by others
- You feel like you understand and are understood by others

## NATURE AND EXTENT OF YOUNG PEOPLE'S CONNECTIONS TO PLACE AND PEOPLE

Young people described a wealth of connections to places and people through their maps, narratives, photography and survey responses. While there was considerable variety in the range of images across the group, in both place and people, there were distinctive themes. Home, virtual worlds, and disability services and schools dominated the places that nearly all young people reported as important connections. Shops and leisure sites are named by several, but with less weighting. Many named sport, and a few people highlighted key events.

Most key places were local, but some people had access to more distant places and hence a more geographically dispersed range of relationships and resources. Relationships with family, friends and disability supportworkers were core. Many young people had loose social networks and weak connections to others. Being seen and known for more than their disability was very important to many young people.



▲  
*At soccer, best mates and best buddies*  
By Jarred

## HOW LIVING IN A REGIONAL COMMUNITY SHAPES BELONGING AND CONNECTION

As part of their research, young people were asked to reflect on what it was like to live in their regional town.

A sense of place mattered to some of the young people, who identified as living in or out of town. Most people lived in town, where the patterns of their lives reflected urban living, with regional effects in terms of limited access to activities, entertainment and availability of goods and services and an expanded sense of distance. Living outside of town was described as an enabler for most of the young people who lived rurally.

Being known in smaller communities was seen in a range of positive and negative ways by young people, and both supportive and intrusive emphases were cast on relationships with other people in their networks and community. Due to a combination of lack of support resources, impairment and felt discrimination it was harder for young people to reach some of the traditional milestones of 'adulthood' in these regional areas, such as getting a job, moving around their community independently, and moving out of home.

## WHAT PROMOTES AND HINDERS A SENSE OF BELONGING AND CONNECTION?

Having a secure sense of place facilitated belonging, and both physical places and the internet were important to many young people. Their sense of place was mostly local, in the places they frequented and found familiar and comfortable. Transport and physical accessibility enabled young people to be in places and activate relationships without strain.

Feeling relaxed and at ease in places was important and disability services, in particular, featured here. Such comfort and security was connected with the people who were in the places. Having enough to do, and sufficient places to go that enable peer relationships to grow, was raised as important by young people with lower support needs in particular.

Being recognised as a capable person was very important to most of the young people, particularly those with high support needs, who were less able to articulate verbally what was important to them. Young people saw themselves as active and contributing family members, friends and partners in support relationships.

Several young people either questioned or disputed the level of agency and authority they had over choice and decision-making in their lives. Others struggled with the inherent tension in accepting care that they did not want, particularly at this life stage.

When young people's expectations of connections were met, relationships with family and friends were mutually supportive, reciprocal and very important to them. Young people felt they contributed to the relationships, and felt a sense of alliance with others. Difficulties or limits with these core relationships had a significant impact on young people's confidence, optimism, and wellbeing. Loneliness was a strong and painful theme for many.



▲ *Unwanted support.* By Jums

## SUMMARY

Emotional qualities of young people's social networks (including formal and informal support relationships) centred on feeling relaxed and comfortable, safe, respected, valued and understood. When young people's needs were not met in their social networks, they were justifiably sensitive to not understanding, standing out, feeling like they did not fit in, and to lack of privacy.

Their most common response in these situations was to withdraw from the places these things happened, either physically or emotionally.

Grief and loss affected over a third of young people in this study, and some young people struggled with lack of acknowledgement of significant losses and traumas. Feeling safe was important at physical, social and emotional levels. Several young people talked about experience of violence and abuse in their lives, with substantial impact. Some young people had strategies to help feel and be safe, but more were lacking in support to cope with serious harms.

### Learning about young people's participation in research

Talking to young people using multiple accessible methods generated a rich and deep picture about their understanding of what facilitates and constrains belonging and connection in their communities. Young people, including those with limited speech and high support needs, were able to contribute with meaning to the research using photography, and to see their participation affirmed and valued in the exhibitions. New knowledge has emerged in this research as a result of the young researchers' reflections on and structured analysis of their work.

Careful consideration needs to be given to issues of consent. Support with data collection and analysis and the use of visual material needs to be carefully managed to safeguard against young people being encouraged in a particular direction rather than supported to make choices of their own. It was challenging to support this at a distance and keep the research principles and process intact.



Zac at exhibition launch ▶

## IMPLICATIONS

A series of implications arise from these results for promoting, sustaining and safeguarding the belonging and connection of young people with cognitive disability in regional communities. The core messages emerging from the research are important both for knowledge and for action.

### Participation

**It is important to young people that their capability is recognised and they can be active agents in their relationships.**

The tension between independence and reliance on others is a difficult one, particularly as young people leave childhood and negotiate multiple transitions. Some young people in this research experienced a struggle between agency and dependency. Having little choice over the provision of needed care made it harder for young people, especially those who need personal care and physical support. Having as much control as possible mattered.

**Young people have multiple identities which need to be recognised.**

Cognitive disability is just one part of young people's identity, and for most of the people in this research, it was far from the dominant part. Their gender, age, locality, cultural backgrounds and skills and interests all played at least an equivalent part in the way that they viewed themselves.

**Relationships are critical for establishing and sustaining young people's sense of belonging and connection.**

When relationships support young people to thrive, they are mutual and reciprocal, and underpinned by demonstrated respect. They develop and strengthen over time. Being lonely impairs belonging, and action is needed for young people who feel lacking in friendship.

**Being known and valued is a core requirement for a secure sense of belonging and personal identity.**

When young people have positive and supportive relationships, personal growth, expression of personal identity, friendship, and feelings of comfortableness and safety are evident. They support young people to thrive. When these core relationships are instrumentally implemented or young people are viewed in a linear, 'disablist' way, this does not occur. Their time is filled, but the recognition and development of their personal identity is neglected, and inadequate attention is paid to their emotional and cultural safety and wellbeing.

### Policy

**The importance of rights-based support cannot be understated.**

Young people had low expectations about participation in the research, and quite a few also about their life aspirations. Rights-based support creatively works in partnership with young people and their families to develop a framework to scaffold their participation and personal development, person by person.

**Support needs to focus on relationship development as a priority.**

Friendship is a critical concern for young people, even more so for those who are socially and culturally isolated. It is very important for young people that they can build on existing relationships, and do not lose their often limited friendships and social networks in the interests of policy and practice approaches which promote their individual interests. Knowing, respecting, valuing, and understanding what is important to young people may mean differently prioritising some activities at a service level (for example, helping young people and support workers understand and put into practice the core skills involving in making and keeping friends).

### **Education and training for young people and supporters in relationship building is needed to give this a skill base.**

A skill set is needed to have the capabilities to make friendships and wider social relationships and to facilitate them. This is particularly important for young people in regional areas, who may have less choice of service provider. Training and personal development opportunities in supporting friendship and personal growth are also needed for those who support young people in various settings, such as teachers, health professionals, disability services workers, sports and leisure settings.

### **A dual focus on developing the capacity of individual young people as well as groups and communities is needed.**

Flexibility in funding and how it is applied to young people's daily lives in regional areas may be transformative in some areas, if rigour and creativity are benchmarks of support and planning. A balance between individual support and opportunities for developing and sustaining relationships in collaborative spaces is important to young people. Group-based programs have inclusion limitations. However, the universalising tendency of large scale policy reform raises a risk of social isolation in individualising everything in young people's lives as the NDIS is implemented, and removing access to the places and relationships which young people say are sustaining. For young people to cultivate places and relationships outside of disability services where they feel in alliance with others, and where they feel a sense of belonging, a dual focus approach to individual and collective capacity building is necessary.

### **Skilled support by those with expertise in youth-oriented environments is important for identity formation.**

Where young people had youth-focused support, they were engaged in activities which were more closely aligned with those of their age-matched peers in the wider community.

### **Virtual connections matter to young people.**

In keeping with the importance of the virtual world to young people, social media and the internet were important conduits for young people with diverse levels of support need in this research – for connection, obtaining information, for holding and promoting images, and for communication, and should be explored further for connecting young people and for information dissemination.

### **Violence and interpersonal harm damage belonging and connection.**

The nature of many of the harms experienced by young people in this research are pervasive, often multiple, and have a cumulative effect. The individual and collective impact of this harm is serious and needs further exploration with young people and those who support them. At structural levels, an increased focus on both prevention of harm and initiatives and strategies to recognise, minimise and better respond to these harms is needed.

### **Grief and loss potentially impair belonging and connection.**

The broad-ranging experiences of grief for young people need to be understood and acknowledged. Services need to ensure staff are professionally developed in relation to loss and grief issues, particularly as these apply to young people with cognitive disability. It may be useful to investigate whether existing loss and grief education programs could be adapted for young people and their carers to help develop skills in adapting to change and loss.

## Communities

**Place is a foundational site for relationships and young people avoid going where they feel unwelcome or unsafe.**

Some people talked about feeling a lack of confidence to participate where they did not feel welcomed, or avoiding places due to fear of what might happen there. The impact of key places closing in regional communities highlighted the importance of welcoming places, as young people talked about having little to do, and missed these opportunities for leisure and social activity.

**Relationships in communities are the major determinant of how young people feel about their town.**

Young people feel known by others in many cases, and some are embedded in their local communities. However, there is both less choice of activities and less privacy in smaller communities and some people find this constraining. The fulcrum to young people finding this a positive or negative experience is the quality of relationships, both in the people being connected with (community members) and the people supporting the connecting (families and support workers).

**Living in regional towns can make it harder to meet transitional milestones.**

Being known has positive and negative implications. Building social networks in smaller communities may be easier for people with strong interpersonal skills. It may, however, prove harder for people who live in unreceptive communities, who have behaviour difficulties, or whose supporters lack the skills to help them promote their positive qualities when forming relationships.

The combined impact of high unemployment rates, lack of public transport, limited disability support resources, community attitudes and discrimination made it hard for young people in this study to reach some of the transitional milestones typical of their age group, such as moving around their community independently, having a job and moving (or thinking of moving) out of home. Having less opportunity to fulfil life goals not only impacts the agency and personal identity of developing young adults, but continues a high level of reliance on their families.

## Research

**Safe, respectful, accessible methods enabled young people to share their experiences and generate rich and deep understanding of their lives.**

Young people, including those with limited speech and high support needs, were able to contribute with meaning to the research using photography, and to see their participation affirmed and valued in the exhibitions. New knowledge has emerged in this research which comes directly from all of the young researchers' reflections on and structured analysis of their work. Careful consideration needs to be given to issues of consent. Support with data collection and analysis and the use of visual material needs to be carefully managed to safeguard against young people being encouraged in a particular direction rather than supported to make choices of their own. It was hard to support this well at a distance and keep the research principles and process intact.

**New practical and conceptual knowledge about belonging and connection emerged and need further empirical testing.**

For young people to feel an increased sense of belonging and connection, learning about it needs to be shared with other young people with disability. As part of this research, young people were eager to see their photography and input shared more widely, leading to the development of the project website. More broadly, our thinking about young people's participation needs to be expanded to include thinking about what helps them to feel a sense

## SUMMARY

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of belonging and connection, and what might put this at risk. Further work with young people with disability in a wider range of settings to confirm or test the belonging and connection dimensions would be valuable.

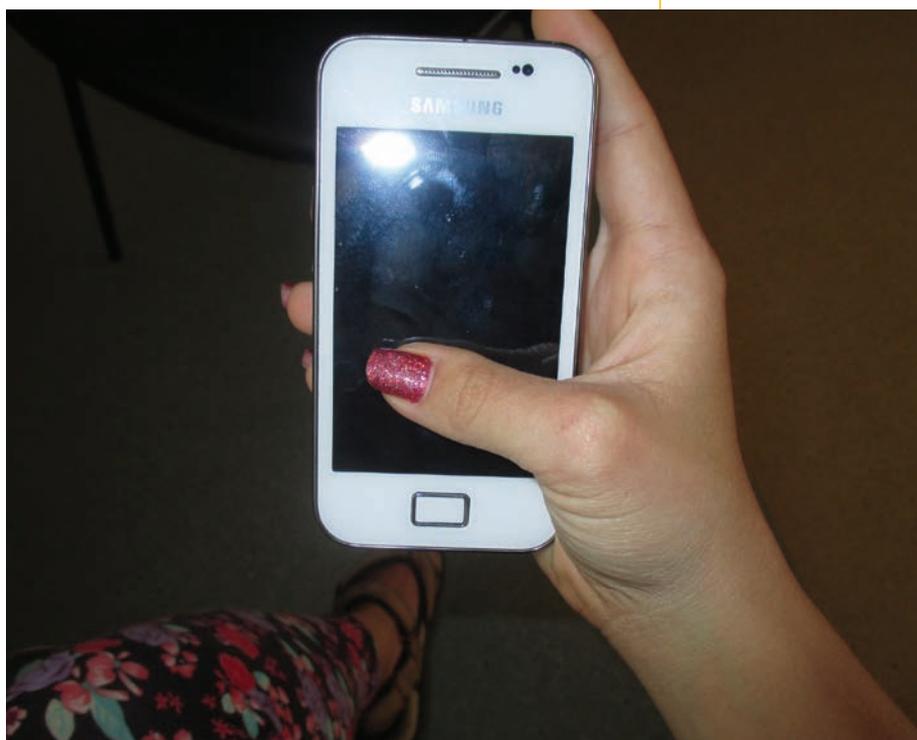
The use of mapping, photography and related activities to support young people to share their perspectives is worth repeating in new research contexts. A differently structured and better resourced survey method would also be of value.

### **The high rates of negative experiences in young people's lives warrant further exploration as a matter of priority.**

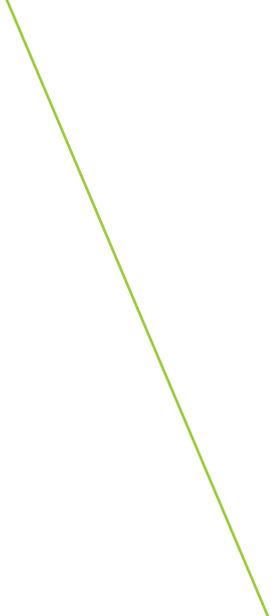
Young people's experience of unacknowledged loss and grief, loneliness, and violence and abuse all featured clearly in this research, even though questions were asked not asked of young people about these experiences. Each of these areas are under researched and inadequately responded to in policy and practice. Sensitive and well supported research methods will be needed to support young people in this work.

### **More research is needed to see how this work might extend or modify theories about recognition, identity, networks, social inclusion and disability.**

The results point strongly to the potential of recognition theory in deepening understandings of young people's desire for mutuality in giving and receiving love (being cared for), rights (being respected) and solidarity (being valued). Further research could apply these key concepts of recognition in assessing the impact of policies, programs and services aimed at fostering belonging and connection.



◀ *A way to keep in touch*  
By Monique



in  
the picture

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AUGUST 2014 - FINAL REPORT

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Sally Robinson

**If you want to read the easy-read report, you can find it on our website.  
Go to [www.belonging.net.au](http://www.belonging.net.au).  
You can see some of the photos from the project on this website too.**