

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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in
the picture

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If you want to read the easy-read report, you can find it on our website.

Go to www.belonging.net.au.

You can see some of the photos from the project on this website too.

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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?

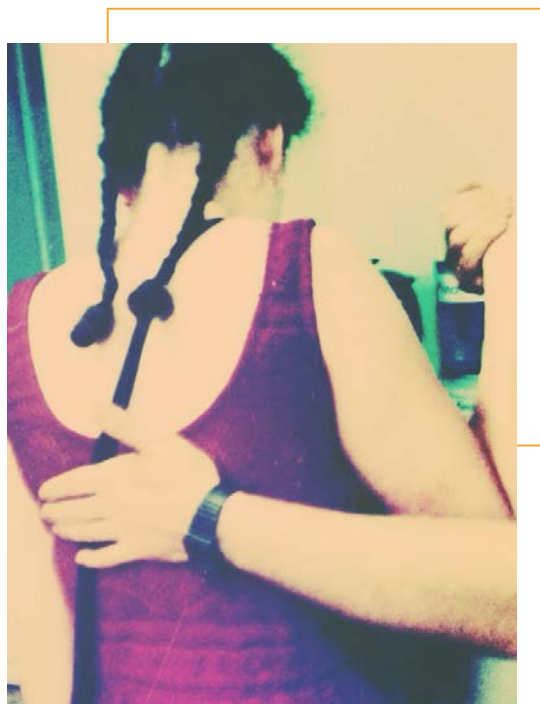
Having a secure sense of place facilitated belonging, and both physical places and the internet were important to many young people. Their sense of place was mostly local, in the places they frequented and found familiar and comfortable. Transport and physical accessibility enabled young people to be 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

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

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.

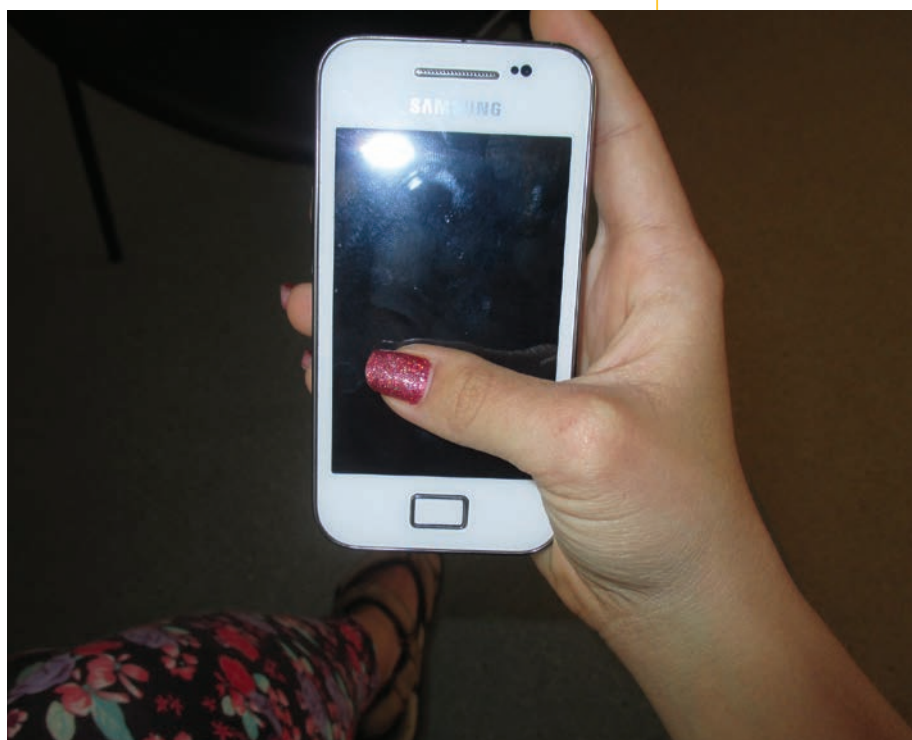
The use of mapping, photography and related activities to support young people to share their perspectives is worth repeating in new research contexts. A differently structured and better resourced survey method would also be of value.

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

1.

About the project

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 investigating the lived experience of belonging and connection with young people with cognitive disability living in regional communities. We posed the following questions:

- What helps in facilitating a sense of connectedness and belonging for young people with cognitive disability who are living in regional areas in NSW, Queensland and Victoria?
- What is the nature and extent of young people's connections to place, space and people within their communities (formal and informal)?
- How does living in a regional community shape the experience of social inclusion/exclusion for young people with cognitive disability?
- How could current policy and programs better facilitate/support a sense of connectedness and belonging for young people with cognitive disability?
- What are the benefits and limitations of involving young people with cognitive disability in participatory research?

We set out to answer these research questions 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 on participating in research were also gathered through the research process.

In three regional communities in Victoria, NSW and Queensland, thirty young people with cognitive disability took part in participatory research in which they researched belonging and connection using a range of accessible research methods including photography, 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 project was conducted by a group of university and community researchers, led by the Centre for Children and Young People at Southern Cross University and including the UNSW Social Policy Research Centre, Strathclyde University, NSW Council for Intellectual Disability and Children with Disability Australia. Our partners in the research were the young people and the organisations who supported them, which were funded disability service agencies in each state. To protect the privacy of the young people the organisations are not named in this report.

This report explains how the project was run, and what we learned about belonging and connection from working with the young people. It is a necessarily detailed report - in keeping with the research method and questions, it was important to document the process of our collaboration as well as the rich research results. A companion easy English report provides summary information for those wanting an overview.

The next section of the report puts our research into a wider context, and provides brief background to other relevant research. Section three gives an account of the project approach. Sections four to seven detail the results of the research – the nature and extent of young people’s connections, the facilitators and barriers, and how regionality affects belonging and connection. The benefits and limitations of the approach for young people’s participation are discussed in section eight. Section nine raises the implications of the research and includes practical suggestions for policy and practice change. Resources which may be useful to people interested in using parts of the research method are attached at the back of the report.

We learnt some important things from working with our co-researchers. Young people with a wide range of capabilities either told us or showed us what mattered to them about belonging and connection. Being known is a core requirement for young people to have a secure sense of belonging and personal identity. Relationships are critical for establishing and sustaining young people’s sense of belonging and connection, and these relationships are the major determinant in how they feel about their regional communities. Living in a regional area can be a positive experience, but can also make it harder to achieve the milestones important to young people as they become adults such as working or moving out. For some young people, loneliness, loss and grief, interpersonal harm and tensions between agency and dependency make these relationships difficult and impair their sense of belonging and connection.

In this research, a decision was made to privilege the perspectives of young people with cognitive disability. We acknowledge the limitation of not representing the perspectives of other stakeholders in the research. However, focusing on deepening understandings of the experiences of young people is a critically important first step in generating new knowledge.

2.

Background

This section of the report gives an overview of key research we have drawn from in designing and implementing the project. Facilitators and barriers to belonging and connection for young people with cognitive disability are identified from previous research, and key concepts of importance to young people outlined. The relevance of belonging and connection to broader debates about inclusion is established in the second part of the section, through research about places and spaces of inclusion and through detailing the rights and policy settings in which the research is situated. Finally, the research framework in which the project sits is articulated.

Previous research about belonging and connection

Previous research distinguishes between belonging and connection. Belonging has been defined as 'a symbolic space of familiarity, comfort and security, and emotional attachment' (Antonsich, 2010, p.645) acquired through continuity of history and memory. Connectedness is the quality and number of connections with people and place. Research with young people has shown that the interaction between place and people is critical to feeling supported, safe and secure (O'Grady, 2008; Pretty et al., 2002).

There is limited research on the ways that children with disability and their families connect with places and people, or about their perspectives on belonging, particularly within regional communities (Carpenter & McConkey, 2012). Existing research shows a number of related issues about belonging and connection in the lives of young people with disability. Recent research about wellbeing with young people with disability found that a felt sense of belonging and connection makes a positive difference to young people's lives (Foley et al., 2012). Drawing together the work of several researchers, a number of key shared themes necessary for belonging and connection can be identified. Friendship, peer acceptance, capability, being valued, and supportive relationships with key adults all appear in literature where young people with disability talk about them as determinants of belonging (Avramidis, 2010; Salmon, 2013).

When belonging and connection are threatened, the places, relationships, and cultures that matter to young people can be damaged or impaired (Graham & Fitzgerald, 2010). Research (particularly in school domains) shows there are several areas in which the impact is seen. The friendships of children and young people with disability are limited, they are lonely, the places they can go are controlled, there are tensions in negotiating support relationships, young people feel and are excluded, and young people's strengths aren't seen by others in their communities (Pavri & Monda-Amaya, 2000; Prince & Hadwin, 2013). Some research has compared feelings of belonging between children with and without disability, finding children with disability had 'significantly lower social belonging and empowerment' (Bramston et al. 2002, p.385). Recent research on social exclusion over time found a growing gap between young people with and without disability aged 15-29 in Australia. On thirteen key indicators, including employment, feeling safe and having support from family or friends in a crisis, disadvantage had increased for young people over a decade, compared to their non-disabled peers (Emerson, Honey & Llewellyn, 2013). Finally, a considerably body of research demonstrates that bullying and negative interpersonal relations are a particularly strong threat to a felt sense of belonging and connection (Foley et al., 2012; Frederickson, 2010).

Transitions

Young people with cognitive disability are experiencing critical transitions in their teens and early twenties – they are leaving high school, perhaps commencing work and/or further study, and developing increasing independence in social and physical community interaction (Salmon 2013). For many, their social, emotional and physical relationships with space, place and people in their communities are becoming less mediated by parents and other adults in their lives as they progress through teenage years, and they are starting to negotiate these relationships by themselves, or with support from service providers, peers or other networks (Flynn & Russell, 2005; van Asselt-Goverts et al., 2013). In addition to these opportunities, risks may emerge for young people in terms of disconnection (Hill & Wager, 2009; Mueller & Prout, 2009).

Identity and relationships

Identity is a term commonly used and less commonly defined. It is a relational concept, and relies not only on our understanding of who we are, but also of who other people are and in return, how they understand themselves and us. Importantly for young people with cognitive disability, while identities are constructed through social relations, the 'tenacity, persistence and governance of specific identities often lead to them being interpreted as genetic, biological or natural' (Hopkins 2010, p.7). Establishing a sense of identity means forming senses of similarity and difference between individual people and across and within different social groups – who we are, but also who we are not. Part of this, for some people, is managing varying and sometimes contradictory identities – such as client and worker, or carer and cared-for.

Research from the UK about the everyday experiences of young people with cognitive disability suggests that relationships are of substantial importance, but also the source of considerable tension (Stalker & Connors, 2005; Flynn & Russell, 2005). A significant amount of research consistently finds friendships to be of central importance to young people, but frequently limited, difficult to develop and subject to damage by intolerant attitudes and behaviour of others (Morrison & Burgman, 2009, Reversi et al., 2007, Salmon, 2013).

Regionality

For young people living in regional Australia, experiences may differ from that of their metropolitan peers in some important ways. Previous research indicates that the smaller size of regional towns, along with unique community cultures, may either facilitate or constrain connectedness and a felt sense of belonging for young people. Limited public transport, support services and employment are features of many regional towns. However, features such as more personal relationships between community members (such as customers and shopkeepers), and a focus on shopping, local sporting and cultural activities have also been shown to be shared features of regional areas (Pretty et al., 2002). All of these potentially impact on connectedness and belonging. Research with young people without disability in rural areas identifies conflicting and sometimes contradictory feelings of inclusion and exclusion in rural communities (Leyshon, 2008).

Places and spaces of inclusion

The concepts of belonging and connection are increasingly used to critically approach debates about inclusion and identity (Nagel, 2011). Research with young people and adults with cognitive disability points to the tensions created by a policy focus on physical presence in the community, whilst focusing little attention on the social and interpersonal relationships which are recognized as being so important for other community members (Milner & Kelly, 2009; Salmon, 2013). Responsibility for inclusion is often imposed on people with disability, who are expected to gain employment, to engage in mainstream community activities and to initiate and maintain a range of social relationships. The role of institutional structures, discrimination and deeply ambivalent social attitudes towards people with disability are frequently overlooked (Hall, 2010). This results in tension for people with cognitive disability, particularly people with higher support needs and people with challenging behaviour, for whom employment is often a difficult goal. Clegg et al. suggest a need to 'shift the moral horizon away from individual attainments and towards the activities and relationships that take people beyond themselves' (2008, p.81).

The policy context of the research

Belonging and connection is particularly topical in the current policy environment. In Australia at all levels of government, policy relating to young people with disability is currently characterised by a significant shift from welfare models to person-centred practices, individualised funding and consequent changes to resourcing. At both state and federal levels there has been substantial policy change in disability support, and a significant investment in funding and planning for moving toward individualised support. In response, non-government organisations (and to a lesser extent schools) supporting young people are facing significant change to their operational structures.

Nationally, the development of the National Disability Strategy (2010-20) reflects concerted effort to bring a unified national approach to meeting the rights of people with disability in the social, educational, legal and services arenas. This includes national commitment to individualised funding at legislative, policy and practice levels through the National Disability Insurance Scheme.

In response to the large-scale national agenda, state government policy strategy has an increasing focus on building capacity in mainstream services and settings to better support people with disability, through investment and skills development. At a regional level, local councils, in line with state planning requirements are required to develop disability action plans outlining commitments to improving access to facilities and services and changing community perceptions (e.g. Victorian State Government, 2013).

Rights frameworks

Australia is signatory to both the United Nations Convention on the Rights of the Child (1989), and the Convention on the Rights of the Persons with Disabilities (2006). Together, these provide a suite of participation and protection rights for children and young people with disability. Of particular interest to this project are the specific articles which detail the rights of young people to participation, safety and involvement in decision making.

At a more conceptual level, the work of Nussbaum is also important in framing the research. Her capabilities approach is what she calls a 'social minimum' approach to human dignity and justice (2010, p.78). Building from the work of Sen, she proposed a list of ten basic capabilities which are relevant to all people and which provide the basic minimum level required for human dignity. These include being able to – maintain bodily integrity; move freely and safely from place to place; have attachments to things and persons outside of oneself unblighted by trauma or fear; live in relation to others; and engage in various forms of social interaction. This theory of social justice specifically considers the circumstances of people with cognitive disability.

Research with young people with cognitive disability

This research lies at the intersection of disability studies and children's rights. It draws on key understandings from both the interdisciplinary field of childhood studies and the social relational model of disability. Such a conceptual framing openly acknowledges the social construction of both childhood and of disability, contests normative narratives of child development and allows for the interrogation of social policy and structural discourses on disability, inclusion, exclusion, and uses of place and space (Goodley & Runswick-Cole, 2011; Sloper & Beresford, 2014; Hill, 2006).

Social geography is a research method which allows us to bring into view simultaneous interests in place, relationships and space which influence young people's experiences of belonging and connection. Using it, we can explore the places which are important to young people, the relationships which happen in those places, and the ways in which social and cultural relations impact on young people's identity in particular contexts – the spaces in which relations with place and people are negotiated (Imrie & Edwards, 2007; Hall & Kearns, 2001).

Participatory research with young people with cognitive disability is growing, but still under-represented in the disciplines which guide our approach to this project – in social geography and in disability and childhood studies (Hopkins, 2010; Beresford, 2012; Tisdall, 2012). There is comparatively little research which works collaboratively with young people with cognitive disability to bring their perspectives to bear on critical questions of belonging, connection and identity.

Sensitive and thoughtful research with children and young people with disability on diverse topics has been completed by a number of researchers internationally, and was used to frame and inform this project. While it is beyond the scope of this report to detail all of these (forthcoming academic journal articles will do so), Sloper and Beresford's extensive experience in working with children with a wide range of support needs in research was particularly helpful in thinking through practical approaches to working with the young people with diverse needs and interests involved in this project (Sloper and Beresford, 2014; Beresford, 2012). We also benefitted from the practical resources made available through the Photovoice repository (<http://www.photovoice.org/>), which makes available archived photography, workshop plans and resources. Aldridge's reflections on the ethics of her work using photographic methods (2007, 2012), and Boxall and Ralph's (2009) discussion of the ethics of internet publication of research images arising from work with children and young people with cognitive disability were formative in guiding our research design. Carpenter and McConkey's (2012) schema for emphasising the policy relevance of participatory research with children with disability was helpful in both the design and report writing phases.

The next section of the report describes the way that we applied this knowledge in the research approach and methods.

3.

Research approach and methods

Consistent with a rights-based approach, this project applied ideas from social geography to explore understandings of belonging and connection with young people with cognitive disability who live in regional communities in three states. Social geography methodologies support the development of ethical research with people who are socially and physically 'othered' or marginalised by explicitly recognising the multiple dimensions of place, space and relationships in which community is represented and negotiated (Hall, 2010, 2004; Imrie & Edwards, 2007; Pain, 2004). The study was mainly qualitative, and used mixed methods across three sites, with multiple contacts with research participants.

Participants in the research

Research relationships were developed with 30 young people using existing community engagement and support programs in three regional communities in three states. These young people were involved in narrative interviews and participatory photography projects based on photovoice. Subsequently, an accessible, on-line questionnaire was consultatively developed and widely distributed to other regional communities to young people with cognitive disability. A further 26 young people participated through the survey.

The photographic research projects were conducted in three comparable regional centres in NSW, Victoria and Queensland. All three sites are defined as outer regional centres (they are more than 30km from a major city), and they have populations between 40,000 and 50,000 (ABS, 2012). Sites were selected based on population size, community consultation, and negotiation with service providers willing to support young people to participate in the project. Services were offered \$4,000 to offset the cost of their participation in the project. Surveys were distributed online to people who self-identify as living in regional communities.

We had initially proposed collaborating with young people aged between 13 and 18 years. As project design and recruitment evolved, it became apparent that the relevance of the research would be increased by including young people in a wider age range, as we could explore more issues of transition with them. Far fewer services were also emerging as available and willing to support younger people to co-research with us, while we received enthusiastic agreement from two services supporting young adults. Accordingly, the research included young people aged between 12 and 25 (refer to figures 1 and 2 for details).

In each of the three sites, there were young people with a diverse range of strengths, capabilities, support needs and experiences. While all the organisations had similar policy frameworks (to support inclusion), in practice the ethos of each was different, and there were also a range of different approaches, both practically and philosophically, among the support workers who assisted young people with the project in each site. In order to better attempt to understand this diversity, and respect the privacy of the young people, the results are not discussed site by site unless necessary, but according to the responses of young people to the themes of the project. Where relevant to the discussion, the ages, support needs and gender of the young people are differentiated. After situating them below, we refer to the sites as site one, two and three in this report. All three services were specialist disability service providers.

Sites

Site one provided respite and recreation support through a range of programs to children and young adults with disability in a regional area. It was located in the same town as many of the young people involved in the research. The town is located approximately 150km from the nearest capital city.

Site two provided a range of support services to children and adults with disability from two locations in the town, including a community centre which the young people involved in this project all used on a regular basis. The town is located approximately 500km from the nearest capital city.

Site three also provided a range of support services to children and adults with disability, from multiple locations in three towns in the region. In the town in which the research took place, the service had three locations, where several service types were provided. The town is located approximately 200km from the nearest capital city.

In each location, the core project components of mapping interviews, photography, analysis interviews, and exhibitions took place. Due to the negotiated arrangement with each service, each project was structured differently, and continued for a differing length of time:



Enjoying the ride ▶
By Monique

Figure 1: involvement of young people in each site

SITE	Co-researchers	Length of time	Young people's involvement	Support from organisation	Involvement with academic researchers
SITE ONE	9 people, 12 – 16 yrs	18 weeks	2 day camp, followed by 3 group workshops, approximately monthly could visit service office to upload photos between workshops	<ul style="list-style-type: none"> • Facilitator • Camp • Workshops approx. monthly (3) • Support workers for group activities • YP could go to office to upload photos between workshops 	<ul style="list-style-type: none"> • 2 day camp (mapping interview & workshop) • Skype with researcher at workshop • Analysis interview and workshop • Exhibition • Website exhibition invitation • Results seminar (forthcoming)
SITE TWO	11 people, 18 – 24 yrs	11 weeks	Individual support for photography within service daily/weekly planning structure	<ul style="list-style-type: none"> • Facilitator • Service coordinator organised practical support • Support workers on daily roster supported young people with photos 	<ul style="list-style-type: none"> • Mapping interview and workshop • 4 days visiting at service (while interviewing) • Analysis interview and workshop • Exhibition • Website exhibition invitation • Results seminar (forthcoming)
SITE THREE	12 people, 18 – 24 yrs	14 weeks	Individual and small group meetings; individual support for photography; launching exhibition	<ul style="list-style-type: none"> • Facilitator • Designated support workers x 3 to support people they know well 	<ul style="list-style-type: none"> • Interview one and workshop (6 days) • Phone, email with facilitator • Site visits (x 6) • Analysis interview and workshop • Exhibition • Website exhibition invitation • Results seminar (forthcoming)

Note: two young people withdrew from the research after the first interview, one each from sites one and three. One did not enjoy the project and the other felt they were too busy.

Young people

Young people involved in the research ranged from twelve to twenty five years. People with a wide range of skills, interests and support needs participated in the research, including four people with very significant support needs. The majority [23] lived in regional towns, with a small number living in outlying villages with populations of several hundred people and four living on farms. Three Aboriginal people and three from culturally and linguistically diverse backgrounds were part of the group.

Survey participants ranged between fifteen and twenty six years or older. As with the photography group, most lived in regional towns, with a small number living in villages and rural areas. A higher number of culturally and linguistically diverse young people participated in the survey [7], and three young people identified as Aboriginal.

Age	Number of coresearchers	ATSI	CALD	Locality
12-14	4			Town 4
15-17	4			Town 3 Rural 1
18-20	10	1	1	Town 7 Village 1 Rural 2
21-25	12	2	2	Town 8 Village 2 Rural 2
Total	30	3	3	Town 23 Village 3 Rural 4

Figure 2: Photographic researchers, by clustered age

Age	Number of resp	ATSI	CALD	Locality
15-17	5			Town 4 Village 1 Rural 1
18-20	5	1		Town 3 Rural 1
21-25	11	2	4	Town 7 Village 2 Rural 2
26 or older	5		3	Town 4 Village 1
Total	26	3	7	Town 18 Village 4 Rural 4

Figure 3: Survey participants

3.1 Research design

Three phased sets of research activities occurred over the life of the research. A summary of the research design is described here, and full details can be found in appendix 1.

PHASE ONE: mapping sites and relationships of belonging and connection with young people

Workshops with support workers and project facilitators were held prior to interviews and workshops with young people in all regions to brief key workers on the project, the research, and the roles of supporters. A resource folder was developed for staff with guides on providing support, ethics, and technical assistance with photography.

Young people and their families were provided with information and consent materials by posted in easy read or pictorial and easy read versions prior to the first meeting with the researcher. The consent or assent of all young people was also discussed and obtained before or at the mapping interviews.

Mapping interviews with young people

The purpose of the first interview with young people was to map their community and relational connections, and to talk about the meaning of these to them. Additionally, we hoped to find out their perspectives on what it means to belong and be connected, and what they expected it would be like to be part of a research project.

Interviews were held in private or quiet spaces within the service environments, and young people were invited to have a support person present if they wanted additional support, either for part or all of the interview. In all cases, interviews with young people followed the same format. Young people who were able to respond to the question were asked about their expectation of the project at the start of the interview. The main body of the interview then consisted of young people and the lead researcher together drawing a map using images or words to show the places and people important to the person, while talking about why these connections had meaning to them. Young people drew their own annotated maps, rather than adding to existing local maps.

At the conclusion of the map making, young people were asked about what they thought it meant to belong, and what it meant to be connected to other people.



◀ Angus' map

Belonging and photo workshops with young people

Following interviews, workshops were held with twenty four young people to establish the photographic projects. Again, these were different in each site, due to the differing requirements of each group. Workshops included practical photography, captioning, small group activities and games which worked through the aims of the project. The individual contributions of each participant about belonging and connection were brought forward (with their consent) into the workshops for group discussion, confirmation and addition.

PHASE TWO: photographic research projects

In keeping with principles of inclusive research (Nind, 2014), the project also built young people's capacity by using a participatory research process based on photovoice, which is an accessible, visually rich research method (Jurkowski, 2008; Wang et al., 2004). This allows for the involvement of young people as co-researchers in research design, collection of data (through photography), analysis of photographic data, and dissemination of results through a public photographic exhibition of key images.

Supporting young people's progress

A series of activity guides were developed in easy English to provide content and process support to young people who were working quite independently as they progressed with their research and also help supporters avoid asking leading questions or unduly influencing the choices of photos taken for other young people receiving assistance with their photography. These activity guides were provided to each of the site facilitators, with guidance for providing them to young people as time progressed, and/or as they indicated they were finding it hard to think about what to photograph to show belonging and connection, or what mattered in their lives. The resource sheets covered topics including my town, portraits and people, a day in my life, getting from A to B, my future, and how do people see me. Appendix 2 includes detail of these.

Young people in each site were supported to upload their photos onto a private account in Flickr, an online photo management and sharing application. This enabled them to caption each photo, store them in a virtual album, and share the developing work with the researcher as the project progressed. Researchers maintained frequent contact with facilitators in all three sites, checking progress and trouble-shooting as the young people took more photos.

A large number of photos were uploaded. In total, 733 images were shared by the young people – 172 from site one, 336 from site two, and 225 from site three. The number of images per person ranged from 8 to 42. This was a manageable number for them and for us.

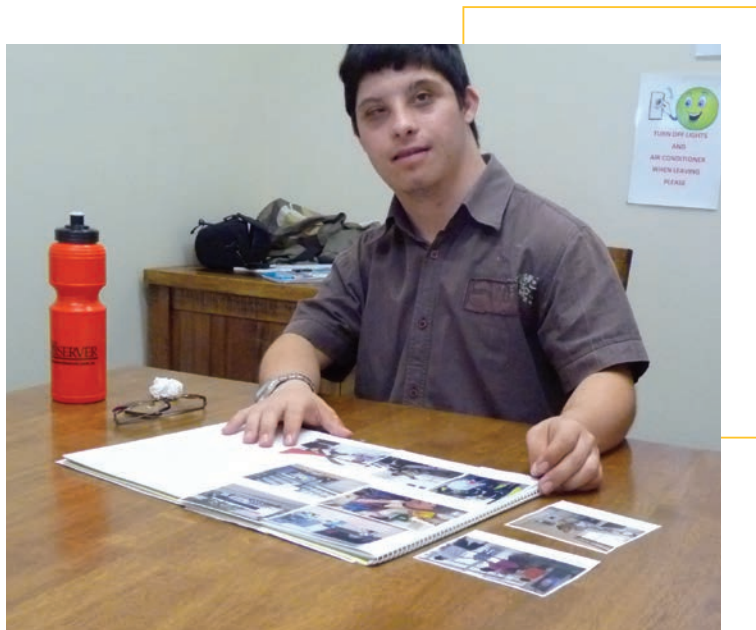
Community sites reflected in the photo research are to some extent mediated by disability services, as sixteen young people were supported to complete the project either partially or fully by their support workers at disability services, and so the activities they enjoy while using services necessarily feature. However, this is mitigated by several factors. Most people also took cameras home and incorporated photos from outside of the service context. The mapping interviews established at the outset young people's understanding of place and people, and where possible their conceptualisation of belonging and connection. Finally, responses obtained through the surveys are highly consistent with the results of the mapping and photo research with young people.

Analysis interviews

At the three-quarter point in the projects, a second interview was undertaken with twenty eight of the thirty young people to explore with them their perspectives on belonging and connection, using their photography and captions as the stimulus. Two were unavailable when the researcher visited, and completed their analysis with their support worker, who had been briefed on the process. They talked about why their photos were important, and which ones were the most important to them. After discussing their images, each person chose key photos as the basis of their contribution to the exhibition and developed a short statement

about themselves in response to open-ended questions about thematic areas appearing in their images and discussion. Through this process, each person analysed their own work, ranking the importance of their photos, coding them by category and theme and providing an explanatory statement. In this interview, young people were also asked about their experience of co-research (the experience and the process), and their recollections of the project purpose.

At the conclusion of the photo research, individual interviews were conducted with key support workers and the project facilitators in each site [seven in total] to explore with them the facilitators and constraints on the young people's participation in the research, and how they supported their participation.



▲ Jarred selecting his most important images.

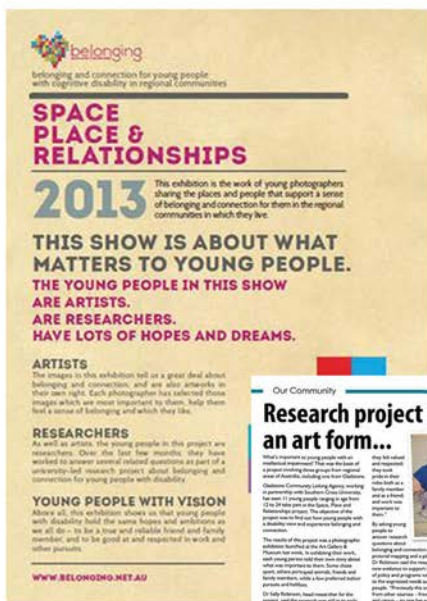
On-line survey of young people with cognitive disability in additional regional communities.

In addition to the photographic project, an interactive on-line survey of young people with cognitive disability who had not participated in the other research phases was developed and run. The survey built on the findings from Phases 1 and 2 and was designed to seek additional information particularly on how young people identify themselves; the relationships they nominate as most important; preferred and non-preferred aspects of regional living; and connections between place and satisfaction. The questionnaire was distributed and promoted widely through organisations providing information, support, advocacy and service provision to young people with cognitive disability. Twenty six additional young people contributed to the research through the survey.

PHASE THREE: sharing results in the public domain

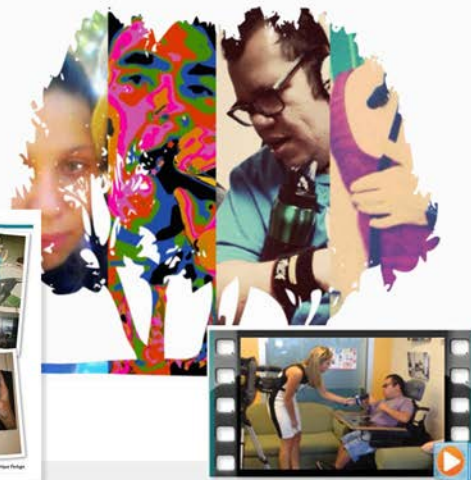
In all three sites, public exhibitions were held in high profile locations to promote the work of the young people as researchers and artists.

All three sites held popular launch events with large attendance (80 – 120 people), music performances by young people, speeches by local dignitaries, and public media in local radio, TV and print. The artistic and research contribution of each young person was recognised in a speech by the researcher at each event.



BELONGING

A Photographic Exhibition Which Speaks



Belonging project website

As the project progressed, the idea of creating a website was suggested by some of the young people, who were eager to both share their photos and see the work of people involved in other sites. The exhibition and website provided an opportunity for group members to demonstrate new skills and to share learning with other people involved in the research, as well as interested community members and a much wider audience.

Seminars for sharing research results

Seminars will be held as the culminating activity in each of the participating regional communities and include young people with cognitive disability, academic researchers, policy makers, family members and other supporters, community members and disability service providers. These seminars will provide an important opportunity for discussion of the key research findings and recommendations. This report and its plain English accompaniment will form the foundation of the seminars.

Data analysis

With the consent of young people (and where relevant, their parents or guardians), interviews were digitally recorded and later transcribed. Visual material (e.g., maps) was photographed, and young people offered the option of keeping their map. Young people's photos from Flickr were downloaded and securely stored, along with their captions.

All data from interviews and the photographic and mapping material was coded for shared meaning using NVIVO software. Codes were categorised, or grouped, into themes according to the emerging new knowledge about key concepts. The analysis of these themes created new categories of ideas about belonging and connection which were tested by exploring the way that certain themes intersected, and the way that multiple themes interacted. 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. These categories were catalogued and used as the foundation for our findings (Richards, 2009; Blaikie, 2000).

3.2 Ethics

This project takes as its starting point the rights, interests, wellbeing and human dignity of young people with cognitive disability. It builds from legal and moral approaches to rights, and is guided by both the United Nations Convention on the Rights of the Child (UNCRC) and of Persons with Disabilities (UNCRPD) and Nussbaum's capabilities approach, as detailed in the previous section. Together, these approaches recognise young people with disability as both able and entitled to participate in research.

Our approach to the project was directed by principles of ethical research with children and with people with disability which

- view children and young people with disability as persons in their own right and as worthy and capable of recognition, respect and voice in research;
- assume young people's involvement in research takes place with the active support of people around them who will provide appropriate assistance and guidance as and if needed;
- acknowledge the importance of research focused on understanding and improving young people's lives and circumstances;
- engage critically with ethical principles of respect, benefit and justice; and
- promote the importance of communication and reflection in attending to the complex ethical issues that may arise in research of this nature (Graham et al., 2013).

Some of the more complex questions which arose in this research concerned working at a distance, researching in small communities, potential harm/distress to young people, and consent (particularly for the young people with higher support needs), both to participation in the project and to the use of photos in different contexts. The methods were designed to try to address these issues as much as possible.

The consent, or assent in the case of people with high support needs, was prioritised. We also obtained consent of parents of people under eighteen and those who needed assistance with decision making prior to the research starting. In addition, we made efforts to ensure that we created a hermeneutically ethical environment (Clegg, 2004) – that we took the responsibility for making sure the research was ethical very seriously and thought it through in all elements of our engagement with the young people. For example, when some of the young people suggested we create a website to promote their photography more widely and so they could see each other's work, we also used it as an opportunity to send each person an invitation explaining in easy English with pictures what it means to have your photos on the internet, the positive and negative implications, and asked them to consent to the release of each image individually, even though they had already showed these images in public exhibitions. This resulted in some people declining to be involved in this part of the project, and some excluding some photos.

Due to the regional locations of the studies, participants in the research have a heightened visibility. To protect their privacy, several measures have been taken in the reporting of the data. The towns and services involved in the research are not disclosed, and we use the states as reference points. Young people either chose a pseudonym or elected to use their own first name at the start of the research. If they were not able to make this choice, we chose a pseudonym on their behalf. We have also used pseudonyms for the participating staff members. The only images included are those for which young people (and where necessary, their guardians) have consented to public release.

A process was developed to help young people think through the level of privacy of their images as they were uploading them, and many images were kept private, or kept between them and the researchers. Some photos in the research are symbolic of personal information about highly sensitive issues which was shared by some young people, most often in a private or confessional tone. These have been treated with great care and many of them are not shared in this report, but rather inform the conceptual framing of the research.

The issue of harm or distress to young people arising from their participation in the project was considered very carefully. We included reference to continuous opportunities to withdraw in the consent material, but were under no illusion that it would be easy for young people to do this. We watched carefully for signs of distress or that young people were confronted by any element of their participation. In two cases this happened, and we talked about the circumstances with the young person and with their support person. We offered access to the free counselling we had available, and to reduced or discontinued participation in the project. Neither of these were taken up, and the young people felt that the issues involved were part of something bigger in their lives, brought into sharper focus by the research. We continued to touch base with the young person and their support person to check that their participation in this research was not making life harder.

In the reporting of the data, sensitive comments made by young people are completely anonymised, and they are referred to simply as young people, and by gender if necessary for context. This is because on some occasions, these people indicated either verbally or through their behaviour a level of discomfort in having their information widely shared. They decided not to include information they had spoken about on their maps, talked at the end of interviews about more difficult topics in a conversational way, and made comments that indicated a level of trust in the researcher's use of the data, such as that made by one person in declining to include a more informative caption about a photo for exhibition which was representative of loss: 'people close to me know what it [this photo] means, and you do too' [addressing the researcher].



Identifying young people's conceptions of belonging and connection

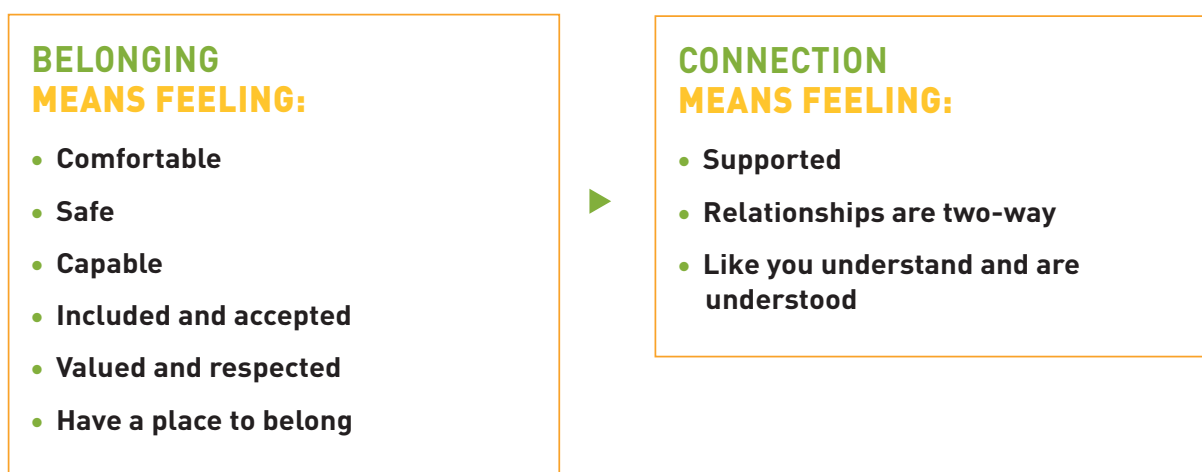
In order to address the research questions, it is necessary to establish an understanding of belonging and connection from the perspective of the young people who contributed to this research. Previous research has offered definitions of belonging and connection which helped in framing an understanding of what might facilitate and constrain experiences of inclusion for young people with disability (see section 2), but little is known about how young people themselves conceive of the constructs.

From both a methodological and a philosophical standpoint, it was important for us to conceptualise belonging and connection from the perspective of young people with cognitive disability. As part of the mapping interviews with young people, they were asked two questions about belonging and connection:

- what you think it means to belong?
- what you think it means to be connected to other people?

Of the 28 young people who participated in the first interview round (2 were away), 16 were able to provide a response to these questions. With consent, their responses were summarised onto coloured notes and cross-checked for resonance with the larger group as part of the workshops in sites one and two.

Figure 4: Young people's initial conception of belonging and connection





Belonging – and not belonging

Young people's responses about what helps them to feel a sense of belonging were affective, and described their felt sense of belonging, and at times the converse. Their responses were clustered in several themes.

Feeling comfortable

Most important was feeling comfortable – in places, socially, and relationally. Zac said that

'for me, what it means to feel like I belong is I can go anywhere and just feel comfortable'.

Nikola noted the impact of feeling uncomfortable on both places and relationships, in saying

'if you don't feel comfortable, you just feel like leaving'.

A third young man pointed out that it can be very hard to understand and interpret social relations, and it makes it very difficult to feel like you belong when you don't understand the social rules.

Feeling safe

Closely connected to feeling comfortable was feeling safe, with some young people identifying physical and emotional safety as important to them in feeling like they belong. The absence of 'mean people' was noted as necessary by Derrick for him to feel like he belongs.

Feeling capable

Feeling a sense of belonging was linked to competence for some of the young people. For example, Ellyse says she belongs at soccer because she's good at it, and Derrick says it's best when he is trying his best and doing well with his school work.

Feeling included and accepted

Being included and feeling accepted were of fundamental importance to several young people. Three young people expressed the importance to them of not standing out, being the same as everyone else, and being able to fit in. Lack of inclusion and acceptance was clearly of painful and far-reaching significance to four young people who provided responses to this question, as the answer of one of them demonstrates:

'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. So, yeah.'

Feeling valued and respected

Being recognised, valued and welcomed were core values underpinning a sense of belonging for several young people. This was not securely felt by some people, as Megan's point illustrates

'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.'

Respectful interpersonal relationships with other people were identified as important for a sense of belonging by some young people. Developing and sustaining these relationships was seen by the young people as something in which they were active agents, and young people had quite high expectations of themselves in these relationships. Two people particularly talked about striving to develop relationships and to being helpful to others to give yourself purpose as key to their sense of belonging. This theme in particular crosses over into young people's understanding of connection, where support and respect from other people also plays a major role.

Have a place to belong

Belonging was emplaced for some young people, and they felt that they belonged in their town because they had lived there all their life, or they belonged in the places where their family were. Membership of a group as supporting a sense of belonging was mentioned by a few people, directly by one who talked about her family's membership in a football club and how they belong there, and indirectly by several who talked about how they feel a sense of belonging in the place and space of their disability organisation.

This final section is a little different to the others, and is more about the conditions that can promote belonging.

Connecting

It was a little easier for young people to respond to the question about what helps them to feel connected than the question about belonging. Their responses were very consistent across groups and individuals, and again, young people focused primarily on their felt sense of connection.

Quinn identified a link between connection and belonging, in saying that when she is connected to other people, she feels

'good. Feels like I belong somewhere.'

Feeling supported

Parents, friends and disability support workers were named by young people as the primary relationships which led to feeling supported. Family support was a robust expectation from two young people, that mum and dad will be there 'because we're family'. Most young people rated friendship as very important, but for young people with more complex family relations, having friends and support from those friends was rated as particular source of support and



▲ Outcomes from belonging workshop in [town], 2013

they said these friendships helped them to feel connected. Two young people talked about friendship being difficult to navigate, and this support not always being reliable.

Support in paid relationships was also named as important by several young people. Zac's example describes its relational nature:

'I have two committed support workers that I like to tell my stuff to, if I'm having a bad day. And one of the things that I have in common with one of them is music. And that is the best thing in the world, cause you can sit down together, write a tune, play it, sing it, and have a smile on your face at the end of it. Yeah, it feels good to have that around. You just feel comfortable with it, you know?'

Relationships are two-way

Reciprocity in relationships helped Stacey and Jasmin to feel connected to other people. Jasmin talked about how she felt it was important to treat other people with respect, and Stacey emphasised how essential she felt it was to spend time and care getting to know a person, giving each other time and attention.

Feeling like you understand and are understood

Being 'on the same page' was important to several young people. Jums says

'You've got to have a common interest, so have something to bond over, so then you form the connection or whatever.'

The importance of communication that is both effective and respectful was raised by three young people, in slightly varying contexts. Nikola talked about communicating effectively so that she and a friend understand one another, she can learn what kind of person a new friend is and she can adapt her style of relating in response. She also saw part of connection as pushing out of her comfort zone and trying not to be shy, in order to connect with new people.

Cookie was at pains to point out that connection does not need to happen in the same room, and 'you can be connected through internet, you can be connected through text – it's all about text, and internet.' Connection to her online community of friends with similar interests was of great importance to her. For Angus, connection was linked to comprehension and inclusion:

'Connected to other people would mean that I could understand them, and they would communicate with me nicely, and I would be just like them'.

This was not easy for some, and it was pointed out by one person that when it is hard to understand the rules of social interaction, it is very difficult to feel connected to other people.

As the project progressed, it was clear that the photography, captions and reflections of the other young people extended and confirmed these responses in valuable and meaningful ways. The research method allowed exploration of these concepts in some depth, and the following section of the report applies this initial understanding of belonging and connection to the data. The report then returns to a discussion of how all of the young people's experiences, reflections and analysis of their research confirmed and extended the early conceptual work of the smaller group.



◀ *Dove belongs.* By Cookie

5.

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 very dominant 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 much with less weighting. Several named sport, and a few people highlight key events. Most key places were local, but some people had access to more distance places and hence a more geographically spread range of relationships and resources. Relationships with family, friends and disability support workers 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.

Responses obtained through the survey were highly consistent with the results of the photo research.

Figure 5: The nature and extent of young people's connections to people and place

PLACE	RELATIONSHIPS	IDENTITY
<ul style="list-style-type: none">• Home• Virtual worlds & tech• Disability services• School/TAFE• Work• Public & community sites• Leisure• Shops• Sport• Highlight events	<ul style="list-style-type: none">• Family• Friends• Boy/girlfriends• Disability support workers• Other service providers• Work - Bosses & co-workers• Wider social relationships	<ul style="list-style-type: none">• Capability• Creativity• Gender• Culture• Transitions• Disability & impairment

5.1 Connections to place

The places important to young people spanned a wide range of sites. Of predominant importance to young people were home, disability services, school, and virtual worlds accessed through the internet and Facebook. Younger people were much less engaged with the disability services system, and their conception of place was mediated much more strongly through home, school, the routines and preferences of their families, computers (gaming, internet and messaging) and sport and outdoor leisure activities. Older young people were strongly engaged with disability services, as they had finished school and were spending a large part of their week in these places. The emphasis in their conception of place was on home, services, work, leisure activities with friends (particularly shopping), virtual worlds (internet, Facebook and gaming), and social activities in their local community. Places and relationships were often mediated through activities, like shopping and leisure.

The key role of home

Most of the young people who contributed to the photo project lived at home with their families (26/30). The majority (22/30) lived in their regional town, with three young people living in outlying villages, and five living in rural localities. Everyone lived in a house.

'That's our big house... Go up the hill, down, until you get to Grand Drive... and it's on the left, on top. Just next to my neighbours, and the one on top is, that's our house, and that's our friends, next door.' [Jarred]

Almost everyone in the photo project nominated home as an important place in their lives. For the majority of young people who talked about home, it was a place where they felt comfortable and supported. Angus, in drawing his map in our first meeting, said that home was 'a very important place' to him. He spent a lot of time and care in drawing his home, and in writing the names of his family members and (deceased) cat next to it. Derrick thought his home was 'fun', and he liked the choice of either playing basketball if it was sunny or just staying inside and keeping warm when it was cold. Matt's home was a source of particular pride to him, as his family had built it and the house next door. He included photos of both of these houses, and talked about his job doing the plaster-boarding, and how he had become quite good at it. Ellyse thought that home was a bit boring, but it was sometimes preferable to the activities that she had to do with her family, such as going to extended family gatherings.

Three young people had moved out of the family home, and into shared group living. One person was supported by a youth service, and the others by disability services. One young person moved between the family home, home-based care with another family and a youth refuge during the research. Two of the older young people had their own detached units on the family property, but still ate meals at the house. One young woman shared with her sibling at the family home while her mum cared for another relative. Several young people talked about living in single parent or separated families, and either travelling some distance or spending time in different locations with parents or extended family members at different times of the week or month as part of their routine.

Many young people found home a less than easy place to be, due to conflict, loss or loneliness (7/30). It was difficult for some of these young people to speak directly about parts of their home life being difficult, and they referred at first obliquely to preferring to be out with friends, staying in their room a lot, and how they take action to protect other family members in a crisis.

Is home an important place for you?

'It depends on what's happened.'

Lots of pictures taken at home were included by young people in their photo sets. These centred on portrayals of family life, including domestic activities, such as cooking and eating meals, doing household jobs such as laundry or out in the shed, leisure activities (particularly computer games and TV and DVDs), friends and siblings mucking about together, flowers in the garden and pets. When asked what they did at home, the activities most nominated by young

people were watching TV and movies, a range of computer based activities (see below), sport and exercise, music (both listening and playing), art and craft, being outside, and spending time with family.

While many of these photos were in line with what would be expected of many young people, in some instances photos and their captions gave context important about belonging and connection which are particular to young people with disability. Some described the way that their lifestyles were mediated by their impairment. Not all of these were identified by the young person. Gemma, for example, included several photos about the daily activities she and her family complete at home to manage her complex epilepsy, which included riding an exercise bike and reflexology.

Very similar emphasis on home was found in the answers from survey respondents relating to place. This appeared as the most mentioned site in the survey.



▲ *Hayley and the banana.* By Hayley

The role of virtual worlds and technology in facilitating connection

Boys and young men were particularly interested in computer games (Nintendo and PS3), although several girls were engaged here as well. Many young people of both genders were using personal computers, particularly iPads and iPods with internet connection.

Most of the young people in the photography project talked about or demonstrated using and enjoying computers, mobile phones and the internet. One young person said that the internet was 'a really important place to me'. He talked about the two way flow of information, and being able to 'share things with the public' as well as getting lots of good resources. Other people talked about their frequent use of computers for accessing music and video, mainly through You Tube. John Sena, for example, regularly looked at his favourites, stored on the computer at his support service, which included music videos and wrestling clips.

Most heavily used by young people with lower support needs were mobile phones and iPods with internet connection. Many people used these for both listening to music and for messaging and Facebook. Making and receiving calls was of comparatively low priority, and primarily reserved for making arrangements with family or service providers.

People with higher support needs tended to use computers and internet technology differently. One young person spent hours each week on Google maps, driving on virtual roads. The morning of our interview, he had been 'driving' through a cane field in Northern Queensland. Leanne was strongly motivated to type on the computer, and spent part of her week using the staff computer to type as staff at the service do. Stephen was very computer literate, and spent a lot of time at home on the computer watching movies and creating his own ideal movie company, complete with logo.



▲ *Look, Google Earth!* By Adam

Almost all of the people with high support needs were familiar with using iPads for photography prior to the project, which proved both motivating and encouraging in their photography for the research. Simon and Rachel, in fact, had hundreds of photos on their iPads. John Sena was really engaged by using the iPad for photography, and worked with his support worker to trial several apps which would allow him to take photos using the whole iPad screen as a shutter button, and they developed a system for taking multiple photos for his research and editing them before loading them onto Flickr.

Facebook

Facebook was in use by a considerable proportion of the young people, and nineteen of thirty discussed their use of Facebook and other messaging services. There were distinctly different approaches to the use of Facebook – some young people used it to maintain contact with family and friends that they knew, and kept their circle of contacts contained and used Facebook conservatively. Others seemed proud of having a large number of Facebook friends, and said they asked people to become friends whenever they saw them on Facebook to grow their friendship base.

Some young people expressed some ambivalence about Facebook, particularly with regard to the impact of negative commentary on the feeds, and conflict between friends over posting photos without consent. Several people said that they don't mind it, but don't really use it much. For example, Megan said that if she gets bored enough she will go on, but calls it a 'time waster'. One young woman talked about how Facebook and Kik Messenger provide access to her friend, who she doesn't see during the week, but at the same time, she can see when she is not invited to social occasions. For two young people in this project, negative experiences with unwanted photographs being posted onto Facebook and very negative commentary being posted about a highly distressing personal situation left them justifiably upset about the ways in which Facebook can cause harm, although they both still use it.

Facebook and computer games were not mentioned by survey participants, who were all completing the survey online. One person said they like using their iPad and iPod.

Disability services

All of the young people were connected with disability services by virtue of the research method – they were recruited through disability organisations. Younger people in site one were using a disability respite service which provided leisure and recreation support. The service is located in the same town that many of them live, although no services are provided from the office, rather being offered as community-based leisure and recreation. They had limited interaction with the disability services system, and while they enjoyed the camp and to a lesser extent the photography group workshops, seemed to place a considerably higher priority on school, family and wider social life than on service related activities.

In contrast, both of the groups of older young people were closely connected physically and emotionally with their services. In site two, all of the eleven young people used the same community participation support program, most of them for three days a week. The service is located in a suburb of the town, on a residential street and within a community centre. A daily program was in operation which put into place the individual plans young people and their families made with workers, centred on developing skills and achieving goals. This included voluntary work, using community services such as local libraries and gyms, going out for lunch or morning tea, and cooking, gardening and art and craft at the centre. Many also used a youth disability social support service associated with the community centre which housed their primary support service for organised recreation. Some people also used the community centre classes for literacy, rhythm and dancing and cooking. On the days they did not attend the service, four people worked at the local supported employment service two days per week. One person worked in open employment three days per week.

Young people in site three engaged in several ways with their support service, which is located in the middle of their town in the central business area. A core group used it fairly intensively, between three and five days a week. They received support to develop and implement a plan focused on personal development in either community participation or transition to work streams. People with lower support needs in the Transition to Work program were focused on going to TAFE or college and receiving support with assignments and reading, learning to drive, help to access sport, leisure classes such as photography and drama, and assisted job seeking. People with higher support needs received support with activities such as making and promoting music, karaoke, art (which was exhibited and sold), moving around the community for social activities, and education. A second group of three young people who had finished using the two year funding allocation provided on transition from school under the Transition to Work program still used the service on an ad-hoc basis, dropping in to check email on the central computers, have their lunch at the communal table, and as Stacey put it,

'see who's here, see if I want to talk to anyone, and then I go again.'

Eight survey respondents were using disability services, but did not emphasise these in their responses, mentioning them as part of the fabric of their lives but focusing more on relationships.

School/TAFE

Younger people were of course at school, and eight young people talked about their current experience of school and five about TAFE. Young people attended a mix of mainstream and special schools. A minority enjoyed school, finding friendship and enjoying lessons. Katie loved music, and liked the fact that she could do her music lessons and see her friends at her mainstream school. Yoshi enjoyed the opportunity to work on the gardens and develop practical skills, and the status that came with being able to drive the ride on mower at his mainstream school. For others, more ambivalent feelings were expressed and for two, open dislike of school expressed. Section 4.5 discusses this in more detail.

Some young people were studying at TAFE during the research, primarily doing work related courses. They universally found it a supportive environment, but the course content difficult.

Six survey respondents were school students, and six TAFE or college students. Again, the responses were consistent with the photo research data, with some comments indicating that some people had found school to be supportive environments, while others had not had such positive experiences.

Work

All of the young people involved in the project were active and busy in their weeks. Ten young people were working in some form of paid employment. Nine were still at school or studying full time, and six had high support needs that would make conventional forms of employment unlikely. Two people were actively job seeking, two were new from school to the transition to work program, and four were focused on artistic and creative activities.

The four people working in open employment worked part time. Two young women worked in child-care at the same time as undertaking TAFE study for child-care Certificate III qualifications. Nikola started work during the research as a catering assistant in an aged care facility. Jarred worked for a fast food restaurant, and had worked there for some time. John Sena earned independent income through busking. The five young people working in supported employment all worked at the same facility on a part time basis, completing a range of process work.

Three women did voluntary work semi-regularly, helping at a kindergarten and in a scrapbooking shop. Rachel in particular really appeared to enjoy this work, as it focused on an interest area for her. Voluntary work appeared in several photos for Rachel, Gemma and Penny.

People still at school did not talk a great deal about work. Matt did work experience at a hairdresser, and said it was 'alright'. Two people reflected back on their work experience. They both enjoyed their experiences working with young children in the support unit at school and at the library, and would like to work there again one day.

Eleven survey participants worked in either supported or open employment. Little was reported on work, apart from a small number of comments which indicated that it was a valued activity.



▲ *Work experience. By John*

Public and community sites

Some young people had a particular affinity for public places in their towns, and felt a connection to them which cemented their feeling of geographic and cultural belonging. Derrick talked about historical buildings in his town, and included some photos of old buildings important to him. Angus spoke about the importance of the town clock tower and war memorial to him as a cultural marker in his town. Playing music in several local venues gave both John Sena and Sam a positive association with these pubs and clubs. Parks with particularly good exercise or play equipment such as flying foxes were liked by Rachel and Simon.

The town streets were important to GI Joe, who would meet up with two close friends and a large group at the train station, the bus stop or Hungry Jacks and just hang out together around the town streets. Yoshi went to the skate park, more to spend time with mates than for the skating.

Survey respondents were asked what they liked about their town. Among their responses were similar public and community sites, and some additional ones which did not appear in the photo research data, such as Christmas and Easter carnivals and accessible playgrounds with liberty swings.

Sites of leisure

Young people took photos of a range of other places where they spent their leisure time, including cafes, pubs, dancing in nightclubs, bowling alleys, and skate parks. They spoke about a wide range of activities that they did with family and friends. Young people who were more reliant on family for social support talked about going to the movies, for a drive, going to the hairdresser, going to

the club to play the pokies, going to local air and wartime history shows, and camping. Those who socialised independently with friends related an overlapping and different set of activities, including laser tag, hanging out at the skate park, riding motorbikes, going yabbying in the creek, going fishing, going to church, going swimming at the local pool and the beach, going to the wrestling, playing and watching live music, going to the gym, archery, and going out drinking and partying.

The survey data was consistent with this data, and two parents who responded for young people with high supports needs added some additional leisure activities including accessible playgrounds, going to church and youth group, and starting a local business to avoid spending all day being taken to the shops by support workers.

The connection to music and music making was very strong for both Sam and John Sena, and they both talked about the places in which they played and watched live music. They had played gigs with bands in a range of local hotels and clubs and had travelled to Melbourne to play in a festival. Three other young people in site three also included photos and descriptions about going out to watch bands, dance and party with friends at local pubs and clubs.

The majority of activities that young people either documented or referred to were in the human built environment, although a few referred to natural sites like creeks and beaches. Activities also range on a spectrum from active to more passive (spectating).

Shops

Shops featured quite heavily in young people's photos, but not in their maps, with the exception of shopping for leisure in young women. Shopping filled several functions for some of the young people, sometimes combined – buying, being in a satisfying place, and being with others. Clothing and discount department stores featured strongly in the photos of some young women. Eight young women described themselves as 'shoppers' and talked about how they liked to shop frequently for clothes, music and DVDs. Most liked to browse in the available shops in the local shopping centre, but for four, the best shopping was in the closest big city (either 2 or 3 hours drive or a plane flight away, depending on location). Not everyone enjoyed shopping. Matt disliked the way the local shopping centre had grown, as it took too long to get in and out to get what you needed. Ellyse and Katie disliked shopping altogether.

Food shops, particularly take-away food, were photographed by nine young people. For Angus, the health risks of take-away were heavily underlined. For others, the favoured nature of McDonalds, Asian noodles and Subway meals were reflected in photos. Cafes were also featured in photos, as places young people went regularly for morning tea during their supported activities.

Of particular interest were photos of shops that people identified as their favourite places. Sam's favourite place was the music shop, which has a whole floor dedicated to drums, which he is renowned for playing well. John Sena said that the games shop was his favourite place, despite the fact that it had a step which prevented him from entering it. Angus' favourite place was a lighting shop, because the lights and statues are beautiful.

Penny took a picture of the best part of her favourite shop:



▲ *Movies are my favourite thing.* By Penny

Survey respondents referred to shops in similar ways, talking about shopping for leisure and the limited number of choices in their town. One person talked about how support workers took her son with high support needs shopping too often, instead of finding more creative things to do in the day.

Sport

Sport was important to twelve young people. Five were very involved in playing at a competitive level. Three young people were heavily involved in sport through Special Olympics, and had travelled throughout the state representing their sport. Jarred and Martin spent a lot of time training and playing sport together, and played soccer and basketball in the same team. Martin was also a competitive swimmer. Rachel did swimming and basketball with Special Olympics, played tennis, and was a member of the Road Runners group. Ellyse said soccer was 'her life', trained twice a week as well as playing on weekends, and associated it with being capable and connected to other people. Her dad was her team's coach. Cookie had recently started playing competitive soccer, and was finding it a good way to get fit and meet new people. Photos of all of these activities appeared in people's photo sets. Sport connected people socially as well as being an important place.

At a level of social participation, people talked about involvement in a range of sports as participants and spectators. Cookie and Possum both enjoyed archery, and found they were getting stronger as they continued to practice. Wayne included photos of himself at the local gym, found it enjoyable and said 'I've got muscles!'. Derrick loved ten pin bowling, because 'the cool people get all the strikes' and said he went there often with his mum. Several people in site two also mentioned ten pin bowling and how much they liked it, despite the bowling alley closing some time ago in their town. Quinn played netball and touch football, but said she was not a sporty person, saying '[service] says I'm sporty but I don't think I am. Playing lots of sport doesn't make you sporty'.

Being a sports spectator was a matter of state pride for young people in one of the sites, all of whom had football team allegiances. In another site, an interstate football final revealed an enthusiastic support by many young people there too, particularly the young men and one woman who is such a fan that she chose the pseudonym Wests Tigers after her team. Ellyse and Bella both spoke about going to football games with their families – in Ellyse's case, this gave her a feeling of belonging to both her family unit and the football club, but in Bella's her reluctance to go had the opposite effect. Going to the wrestling and watching wrestling and Ultimate Fighting Club on the internet was a lot of fun and both sport and entertainment for John Sena and Zac.



▶
At soccer, best mates and best buddies.
By Jarred

Highlight events

Many young people included references and photos of highlight or hallmark events which occurred during the research period. These included holidays overseas and regionally, large pop concerts, 21st birthday parties, a debutante ball, and a community ball. With the exception of the balls (organised through school and service) these events were organised with family and attended with family (in the case of holidays) or friends.

5.2 Connections to people

Relationships with other people were of central importance to the majority of young people. With limited exceptions among people with high support needs, young people talked about the importance of friends and family in their lives. The impacts of interpersonal relationships were felt in both positive and negative ways. Work relationships and relations with other people using the same support services were distinguished from friendships by some people, but this is harder to determine for people with high support needs. Disability support workers played an important role in the lives of many young people. Service providers such as teachers and health professionals also featured in young people's narratives. Wider social relationships with neighbours, family friends, local business owners and shopkeepers, and taxi drivers formed a backdrop of looser social connection for many young people. Here again, responses from the survey were consistent with the photo research.

Family

Relationships with family was a dominating theme in young people's maps, photography and interviews. Young people talked about their family, especially parents, as a major facilitator of activities, learning and practical and emotional support.

Parents and nuclear family

Some young people were very close to their parents, and talked about loving them, feeling a good connection with them, and being helped and encouraged by them. Derrick talked about his parents going with him to places he liked, such as ten pin bowling, golf and the basketball court, and for going for drives with his dad. Angus talked about how 'my family always encourages me to do stuff'. In selecting photos for the exhibition, Gemma found it very stressful to choose between photos of her family life, eventually keeping them all, as they were all very important to her.

In their photos, young people primarily described family life which was oriented around shared daily routines of living and mutual support and care for one another. Younger people under eighteen, still living in their family homes, talked about patterns of family life which were similar to those of other young people their age in this locality. Older young people with lower support needs talked about increasing independence from family life in their social lives and activities, but most still remained living at home. It was important to some young people to show, and relate, that the provision of care and support in their family is mutual and reciprocal.

Matt said

'I love my family, and I try to look after them as much as I can.'



▲ *My family, my mum and dad in the kitchen. We help each other. By Jarred*

Martin talked about how he helps his mum with housework, and keeps an eye on his dad in the shed so he doesn't injure himself in any way. Angus said he taught his mum how to use the computer 'a lot of the time'. Cookie, Monique and Megan talked about their household responsibilities.

Ten young people talked about difficulties in their families of one kind or another which negatively affected the way they felt. For some, a foundation of love and support was described, within which they felt a lot of arguments with parents and siblings occurred. Others described repeated emotional and physical conflict within the family, being let down, not feeling able to trust family members, being taken into care, and being 'given a hard time' about core parts of their personal identity. The impact of these significant events and relations within their families was profound, influencing other domains of their lives and identities. Section 4.5 discusses this in more detail.

Siblings

Sibling relationships featured in young people's maps, photos and conversation in many ways. For some, sibling relationships were close and loving, particularly those who were youngest in the family, who tended to look up to their older siblings. As would be expected, some people's siblings had moved out of home, and several young people mentioned brothers and sisters who had moved to capital and regional cities, as well as those who had stayed in the town. Four people in separated families had non-adult siblings who lived with their other parent. Most often, they missed their siblings, and looked forward to seeing them. Two young people from big families commented on the nature of their sibling relationships, Matt saying 'my brothers and sisters stick up for me, we are close', but Yoshi wishing for a little more attention from his mum among competing siblings. Less harmonious sibling relationships were described by seven people, who talked about arguments and disagreements over a range of issues. Some of these were more routine, for example Gemma was particularly keen to help her parents, and talked about how upsetting she found it when her sister who lived away from home took over some of her household jobs when she visited. Two young people, however, talked about serious conflict involving siblings, one that resulted in police intervention and one resulting in both living in separate housing. In both of these situations, neither of the young people in this study were the instigators of bigger family traumas which were in play, and which affected their actions and reactions to the situations.

Extended family

Extended family, particularly grandparents, were very important in young people's lives, with twenty people including them on maps or in photos. The perception of many young people about their grandparents is well summarised by Jums, in speaking about her grandmother:

'even though she babies me and it annoys me, I kind of like it. Cause she's the only who looks after me like that, and I like the attention... Not babies me, looks after me. She looks after me. I like it, even though I whinge, it's good.'

Grandma was the only person Leanne mentioned independently, and the only person she drew on her map. She said

'I have a nice Grandma, do you?'

a long sentence for her and an unusual initiation of conversation. Monique returned to the interview room to add to her map because she was worried that she had left her grandparents off her map, and they were important to her, as she spends school holidays with them. Her grandparents came to the exhibition and were very supportive of her work. Wests Tigers made a long list of all the family members she could think of on her map, extending down one side of the page. Cousins, uncles and aunts formed a social network for some young people. Extended family seemed particularly important among the many people who talked about loss or tension in their nuclear families.

Pets

Pets were important to a considerable number of young people, appearing in the photos and maps of seventeen people. Young people talked about their pets as part of the family, and were clearly fond of them. For two young women, relationships with their pets were centrally important, and they talked about the sense of closeness they felt to their pets and how strongly they loved them.

In surveys, little detail was provided on the quality of family relationships, but the same range of relationships with family members were nominated as important by young people.



▲ *Chrissie.* By Nikola

Friends

Friendship was extremely important to many of the young people. When they felt satisfied about the number and quality of their friends, young people made comments that indicated the role of friendship as both status enhancing and a key facilitator of feeling included. When friendship was not viewed by young people as positively, they talked about tensions and limits which impacted on their personal identity, the desire for more or different friends, and loneliness. For several people, and particularly those with high support needs, friendship was primarily expressed through a service lens. At times, narrow conceptions of friendship, and a fragility or lack of depth in relations between peers was observed.

Depth in friendship

When young people talked in positive terms about friendship, they talked about how their friends both walked alongside them in enjoying good times, and also gave them meaningful and practical support when they were struggling. Friendships with depth and shared meaning promoted feelings of belonging.

Jarred and Martin are in the fabric of each other's lives, and documented their friendship quite extensively in their photos across the project in terms of both depth and diversity of locations. They both included photos of sport training (basketball and soccer), hanging out at home playing computer games, taking in the washing at Jarred's house, and at Jarred's 21st birthday party. Martin says Jarred is a 'great mate' and



▲ *I enjoy being with the people I love.*
By Sarah

**'I normally go over to Jarreds - stay up all night, and play wicked games.
We normally go to bed about 12 in the morning!'**

Similarly, Quinn talked about how she goes to her friend Anna's house most weekends, they are planning to move out together in a year, and how their families go camping together annually.

Yoshi and GI Joe both talked about having 'heaps' of friends, and rated them highly. They both moved about their community more independently than many of the other young people, and maintained very independent friendships. GI Joe said being with his friends was important to him because they looked after each other, they had fun and he felt safe and comfortable with them. This was similar for Stacey, who said she liked to have lots of friends from different parts of her life.

Bella said her friends see the 'other' side of her - the happy side. They hang out together at school. She feels that her closest friend really knows her, and that her friends have been responsible for helping her 'get the happiness back into her life' after a difficult period. Zac talked about the trustworthiness of his best friend, saying

'he's always great. You can talk to him about anything. He listens and he's very respectful about what you can keep private and you can't tell anyone else, so that's good.'

The status-enhancing aspect of friendship was highlighted by both Jasmin and Bella, who had friends who had become mothers during the research project. Jasmin talked about how pleased she was to become an 'auntie', and Bella chose the photo of the young mum and baby sitting on the hospital bed as one of her exhibition photos. Jarred's 21st birthday party occurred during the period of the research, and this featured in the photos of Jarred, Martin, Monique, and Rachel, where it was a high status event. Friendship that promoted the capability of young people also featured in some photos.

▼ *Duet. By Luke*



The connection to other people provided through Facebook was particularly valued by young women. Wests Tigers said

'When I get on Facebook, I pop up and they pop up and I start talking.'

Jums talked about a big sense of loss when her iPod broke and she lost access to Facebook and music until she could replace it. When asked what helps her feel like she belongs, Cookie talked about the sense of support she felt from an online community of friends who have connected through a shared interest in anime (Japanese animation):

'Cause I've got people on there to talk to. And if I feel down, they hug me, even though it's not a real hug, I don't mind... So, I'm kind of used to having that online part of me on'.

Seven survey respondents mentioned friends as important to them, and portrayed satisfaction with their social relationships, including comments such as

'I like to be friendly. I like doing things with my friends'.

As with the photo research, many people discussed limits in friendship. A distinction between the two methods is in the directness of the responses, with survey respondents addressing lack of friendship more directly. Three of these responses talk about the desire for more or deeper friendships, and four people included responses in which they spoke about loneliness:

'I don't have a lot of friends and my illness prevents me from doing things'.

Loneliness is discussed further in section 4.5.

Friendship through a service lens

Friendship, in expression and form, was mediated by the service environment for many people who participated in this project. This can be attributed in part to the fact that young people spent a considerable amount of time, and were emotionally invested, in the place and people. The project was designed and implemented through disability organisations, and some people completed it by taking photos at the service and out in the local community, meaning their 'service life' had a stronger focus in the photographic phase. In some cases, young people's lives also crossed over multiple service environments due to the nature of regional living, as there were only a limited number of supported activities available to people with cognitive disability in the community, and several people did the same sets of activities.

While each site took a different approach to facilitating the friendship relationships between young people, some general trends could be seen. People with lower support needs had developed more organic friendships based on preference and activities, and sometimes extending beyond other people also using the service, although these people formed a core group for most, along with old school friends. Younger people were less engaged with the respite service they used, and their friendship connections arose primarily through school and family. There was a greater tendency for people with higher support needs to be prompted by support workers to describe other people who used the service as friends. They did spend a lot more time together, and get to know each other well. People with high support needs were not able to articulate their feelings about friendship or loneliness in the research, beyond agreeing when service providers suggested that certain people were their friends. Leanne and Penny both included photos of people they appeared to like, based on their reactions to the photos.

Some people had friendships expressed with warm and affection, and demonstrated through comments, photos, the presence of friends independently cited on maps, and observed while visiting the sites over several days. For example, Monique independently named Gemma and Rachel as her friends, and when asked what sort of things they got up to together, said with a laugh

'We get up to mischief sometimes!'.

Other relationships appeared based more on proximity and shared service use and the encouragement of service providers than the expression of mutual warmth and regard. Quinn's comment in response to who she spends time with at the service highlights the distinction:

'I've got people here - Jasmin, Harry, Pete. If they're not here, it gets pretty lonely. I'm used to my normal friends.'

When asked 'What do you like to do with your friends?' Jarred's response was couched in program terms, 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 people talked about both workers and other service users as their friends. Other people talked about how it was important to them to have relationships with both workers and people using services. For some of the young women, who contributed to a facilitated personal development and support group, the shared nature of participation by young people and support workers was valued and the group rules helped them to feel confident in sharing personal information. Cookie said

'we talk about very private stuff, and what happens in [the] group stays in [the] group'.

Zac's reflection is very illustrative of the different roles he understood people to play:

'I like coming here and being comfortable with myself. And that I can come in here and tell the support worker that I'm really comfortable with anything. And I've made a lot of friends. That's the best part about it, that I can come here and make friends'.

Boy/girlfriends

Nine young people talked about relationships with boy or girlfriends. In five of these cases, these relationships weren't discussed in any detail, and the boy/girlfriend didn't feature on either the map without prompting by support workers or in the young person's photos. Two other relationships developed during the course of the research. In one case, both the young people were involved in this project. The young woman talked excitedly about their first date in her interview, while the young man was more circumspect, but included photos of them together in his Flickr set. Neither of them included a joint photo in the exhibition. Another young man had been with his girlfriend for nearly a year. In a photo caption, he called her 'the love of my life'. However, there may have been some tension in the relationship, as they decided to go with other partners to the debutante ball, in case they split up during the preparation period. He said this was 'definitely' a good decision, but chose the debut photo of the two of them as his large exhibition photo.



▲ *Loved and special.* By Jasmin

Jasmin talked about how important her boyfriend was to her, and how it had been difficult to navigate the ups and downs of relationships. Wests Tigers had an enthusiastic friendship with Wayne, which she would very much like to extend beyond the friendship they have at the service. She called him her boyfriend, but he saw her as more a friend, according to their support worker.

One partner and one boyfriend were mentioned in the survey, where the liberating qualities of anonymity are evident, as the latter is discussed as being 'too sexy for his shirt'.

Disability support workers

Relationships with disability support workers were core in many of these young people's lives. Again, this relationship had less resonance in the lives of younger people, who had less contact with disability services and were more influenced by family. Most young people did not talk a great deal about the qualities of the relationships with their support workers, beyond limited descriptive terms. It was without doubt difficult for them to speak about unequal power relations, particularly for those who had a support person in their interview, and these people were not asked directly about their relationships with support workers. These relationships appeared in photos and commentary and were observed on the visits to the sites.



▲ *Jamming together.* By Luke

There is a delicate balance between support which enables and that which constrains personal development, relationships and a sense of belonging and connection. It is difficult for research which is conducted at a distance to make too strong a determination about this balance in relationships between support workers and young people in this research. The warmth and rapport in ongoing relationships between support workers and young people was clear to see, and many times, having support workers involved in the interviews and photographic processes gave reassurance to young people and helpful additional context to the researcher. However, it can be seen in the observational logs and in the contributions of young people through their maps, photos and interviews that where the interests of young people were less closely held in view by support workers, or where deficit conceptions of disability prevailed, there was less space for the perspectives of the young people to emerge, and approaches to their participation were more programmatic.

When young people were respected and their contributions and potential fostered by support workers, the potential for this relationship to promote personal growth and to help scaffold the transition from childhood was evident in the photos, maps and dialogue with young people. Quinn included photos of her support teachers from school at her school formal in her photo set, and talked about how important they had been to her. The role of one support worker with several young people who played and recorded music seemed to provide a combination of practical support, motivation and a base of reassurance from which creativity welled.

Positive and supportive relationships with particular support workers were important for young people's feelings about being known, valued, and equipped to engage with the wider world. Two examples illustrate this. Rachel had included several photos from home about music and the ribbon she used for dancing, so it was fairly clear she liked to dance. She also included a photo of dancing class with her support worker, Jane, teaching. The following interchange shows how much she is motivated by Jane's presence in the class:

Why do you like dancing, Rachel? I like Jane. Do you like what she's teaching you?
'Yeah. She's nice. I like her. Jane's nice. I like her. Very nice. She's nice, that Jane.
Yeah. Is that the best thing about dancing? Yeah. I like Jane. Jane's just there'
[pointing to photo].

Zac included a photo of the whiteboard with names of workers and young people, which changes daily and allocates workers to the people they support for the day. When asked if he checked it when he arrived in the morning, Zac 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 [depending on who I'm with].'

For survey respondents, relationships with support workers were important, but less so than for people in the photo research. Only four respondents nominated support workers in answer to a question about who is important to you. Relationships were described as supportive and enabling, but also at times vexed when support workers did not put effort into their work and took people to wander around the shops instead or doing more creative or imaginative things young people would enjoy more.

Other service providers

Eleven young people talked about relationships with teachers at school. Five found key teachers at school supportive and easy to talk to. Derrick said he usually did 'health and human' and 'circle time' which involved sitting in a circle and talking to people. He said his teachers helped him, were nice and 'I do just talk to them'. Quinn included photos from primary school in her photo set, and said

'I love that school. I still talk to - if I see the teachers around, and they still know me.'

Ellyse was more ambivalent about school, finding her teacher motivating and helpful, and enjoying the strategies he used to make learning fun, but finding her class disruptive which made it hard for her to learn. She was allowed to play music through her headphones during class to help with this, but said sometimes couldn't even hear the music. Two other people found teachers unfriendly and unsupportive, with one saying

'They don't understand people. They don't understand me.'

At TAFE, young people consistently found tutors to be supportive, and also their classmates. Gl Joe's perspective was that at TAFE, teachers were nice, helpful and knew what they were doing.

Health care providers were mentioned by three young people with significant physical disability. Two of them talked about ongoing relationships with their doctors, Gemma talking about going to a capital city to visit a specialist regularly, and being pleased that she was able to call him by his first name. Wayne included photos of his doctor, medical centre and the medical supplies he needs to get through his week in his photo set. He didn't seem very interested in these, or select any of these for exhibition, and his support worker wondered if his mum encouraged him to include these to give a picture of his daily life. Wests Tigers had a long stay in hospital and was seriously ill during the research. She talked about the mixture of quality of care she received in hospital, and how poor medical care and poor delivery of information affected how she felt about her wellbeing and her health outcomes.

Survey respondents mentioned a similar range of people, and also a pharmacist.

Work – bosses and co-workers

Of the thirteen young people who were working in paid or voluntary capacities, most were positive about relationships with their employers and colleagues. Little information was shared about work relationships by young people. Jarred said the people at his work were

'like my friends. And they are very happy with me.'

He described himself as a 'professional worker' and said his bosses told him that he was doing a good job, and he had recently been given an award for his work. His bosses came to the exhibition to see his work. Nikola said she was casual, covering for people who were ill, and she saw it as a stepping stone to another job she wanted more, as an assistant in nursing. The five people working in supported employment all liked the fact that their friends worked there, and Martin said the money was good. People working in voluntary jobs and work experience said they enjoyed it and liked the people they worked with. These jobs seemed less reliable and the connections with people at the workplace less secure. People weren't able to name other people at these workplaces, but said they were nice.

Survey respondents did not emphasise work, apart from two people saying that it was easy to get to and they liked their work.

Wider social relationships

Young people talked about wider social relationships with a series of people – neighbours, people they had been to school with, people they knew in their town (people in local businesses, buskers, taxi drivers), others using the same services, co-workers, and family friends. These relationships formed a loose social network in many people's lives.

Survey respondents also mentioned a similar range of people, including a church community and its youth group, and people involved in the same wrestling team.

At the exhibitions, young people invited people important to them to view their work as researchers and artists. The range of people attending is indicative of their social networks. The young people and their immediate families (or some members) were involved, and a broad range of invited guests. These included extended family (especially grandparents), bosses from work, neighbours, friends and family friends, local business owners, ex- and current school teachers and support teacher aides, other people who used the service, disability support workers, and workers from other agencies young people were or had been associated with. As well as the number of guests (ranging from one to over twenty), of interest was the range of people attending at the invitation of young people and their families. Some had extensive informal and family networks, and some minimal. Some people had little service engagement, and some extensive amounts. Some young people seemed comfortable to be engaged with formal disability support, and others less so.

Young people in one town were considerably more widely known than in the other towns, and their photos and conversation showed a wide range of engagement with people working in local



▲ *My favourite drummer. By John*

businesses, music and entertainment venues, and with street musicians and taxi drivers. This level of engagement was both due to their personal qualities and an outcome of their disability support, which was explicitly focused on linking people to the community through their individual interests.

While support from disability services was undoubtedly important for forming of these wider relationships, the agency of young people should not be underestimated. Zac and John Sena both described the conversations they struck up with taxi drivers, and could name all of the local drivers and which ones were nicest. Sam is known by most in his home village, and says that when he walks down the street by himself, lots of people say 'hi Sam, how you going?'. He has a significant communication impairment and many ways of showing his friendship and caring. On the morning of our workshop, he arrived with potato scallops for John Sena and their support worker, a semi-regular treat he provides. He was concerned that I would miss out, and recommended the best shop to buy them, and who to talk to there.

Most young people with lower support needs distinguished between friends and other people they knew who came to the same service. Some people identified people they didn't like, or people they didn't know well. Two talked about conflict with others over time, which had been resolved with the assistance of support workers. People who lived outside of their family home clearly distinguished housemates from friends. Stacey said

'We're not really friends, but I don't want to live with my friends. Cause you have fights and stuff, and then it might hurt the friendship.'

People with higher support needs were encouraged by support workers to name co-users of services as their friends (see previous section), and in fact they may have been. It was not possible to determine whether these young people distinguished between friendship and co-use of service, apart from Rachel, who independently identified another young person and a worker as her friends, and then agreed with the support worker's suggested list of other people who were her friends, but went on to only include photos of the originally nominated two people in her photo set.

5.3 How these connections affect young people's identity

Young people in this research were diverse in many ways. They had widely ranging ages, interests, support needs, came from different cultural backgrounds, and had ranging levels of worldliness. Amongst this diversity, there were common threads that seemed important to young people about their personal identity. The issue of identity in the research was approached tangentially, rather than by direct questioning or using an assessment scale. As part of the photographic analysis, young people came up with some key words and phrases to describe themselves which accompanied their photo collage. This was displayed in the exhibitions in each location. These constructs, together with the photos and dialogue with young people, give insight into what is important to them about their personal identity. This method of approaching identity did not often yield what people might be more expected to say – their gender, age, locality or religious affiliation. Rather, the identity constructs emerging concern the roles that young people perceive for themselves, particularly with respect to capability and creativity; how gender and culture might nuance the experience of belonging and connection; transitions; and disability and impairment.

Capability

Being viewed as capable was identified as important to almost all young people in this research through their photos, collage statements and in interviews. In many examples, young people included photos of themselves completing activities they are good at or proud of, and twenty six statements on their collages centred on self-identified qualities such as being athletic, artistic, a good cook, dancer, worker or taking care of others. This was particularly true of people with high support needs, who had fewer photos of relationships and more photos about capability, and can be seen in the number of 'I can' or 'I do' statements accompanying their photos about the things

that they achieve. For example, Leanne chose several photos of herself writing, a greatly preferred activity which she spends a lot of time doing. While she can't write words, she spends a lot of time practicing and is very motivated to write and type. She chose a photo of herself writing for her large image to be displayed in the gallery, saying 'Leanne is writing. Writing a big job.'

Twelve young people talked about ways in which they actively took care of their own wellbeing. Angus was concerned to maintain healthy eating, and two older young people stressed that they only drink in moderation or drink soft drink at pubs. Three people used a suite of strategies to manage complex health conditions. Eight young people talked about the benefits of the exercise that they regularly did for their wellbeing. Three survey respondents included reference to being fit, strong and healthy. Possum said

'the doctor said "you need to exercise" and gave me a talk about exercise, for a very long time. And now, I go on exercise. I've been low fitness. Not now though'.

Three people who experienced depression and anxiety talked about the strategies they had to keep themselves feeling well.



▲ Bradley's collage, as exhibited.

Creativity

Seven young people strongly identified as creative, and talked about how they were shaped by music and art. Their lives included a deep engagement with either music or art in various ways. For example, during the course of the project, Zac was starting a video documentary about the lives of John Sena and Sam to show a positive view of life as young Aboriginal men with disability. He said one of his main motivations was to educate people, particularly support workers new to the field, who make assumptions about Aboriginal men and people with disability. In their collage statements, a further thirteen statements were made by young people who talked about their enjoyment of drawing, art, photography, woodworking and craft, and how they felt this helped them to express themselves.



▲ *Singing the love.* By Zac

Nikola said

'I have a creative mind.'

Possum had a strong interest in local history, including photos of old farm machinery, and saying

'I am fascinated by the history of things and how they change'.

Music was very important to five people as performers. Three people wrote and performed their own songs, and had made their own CDs. Being seen as musicians and performers was a core part of their personal identity. The music lessons and performances by Katie and Ellyse were also important to them in promoting their capability and creativity and in maintaining their wellbeing.

Stephen's identity was constructed around a (fictionalised) television network and the remakes of his favourite movies, which he described as in progress. Movie making and television network operation are his primary conversation topics.



▲ *P-51 Mustang at the [local] Air Show. By Possum*

Gender

Some gender differences in the photography and dialogue are apparent between men and women, boys and girls in the research. In their collage statements, young women and girls talked more about their relational qualities and interaction with other people, including reflections such as

'I am kind'

'I am a nice person'

'I'm a really down-to earth person'

'I'm soft-hearted, sociable and easy-going'

Men and boys focused more on their self-identified capability, strength and interaction with structures, including comments such as

'I am confident'

'I am a professional worker'

'I'm a sportsman'

'history is important to me'

Some older young women took photos with friends in places and poses which showed them having a good time in quite glamorised ways – at a ball, the beach, out dancing, and drinking. In these photos, they are seem conscious of the image being portrayed in the photo, and

some of the captions such as 'heey, sexy ladies!' seek to maximise this. Young women also talked a lot more about boyfriends and relationships than did young men, and invested a lot more emotional energy into these relationships.

Culture

Culture was of particular importance to the three Aboriginal people involved in the research. Two of the three spoke of their pride in their culture and how it was a part of them. As mentioned, Zac was making a video documentary to promote both Aboriginality and disability in his friends, with the purposes of education and expressing creativity.

Culture was not mentioned by the people who came from culturally and linguistically diverse backgrounds. Three people talked about their religion and church and how this was important to them.



▲ *Cool Bundjalung man.* By Luke

Home location

The regionality of the young people was also important in shaping their identity addressed fully in section 4.3. Six people embraced the rural location in which they lived, making comments like

'I like where I live because it's open.'

A small number found their regional town stifling. Some young people felt a sense of belonging in their town because they had always lived there, or because their family were there. Many did not critique their town, but simply accepted it as a backdrop to their lives, as it was the only place they knew and they had no comparison points.

Transitions

Young people in this research were experiencing a number of life stage, role and setting transitions. These can overlap but are distinct, for example adolescence to adulthood, scholar to worker, student to TAFE or disability service. The young people in one site were all of school age and still in full time education, and in the other two sites, had left school. This was the most abrupt transition in people's lives, dictated by the education system rather than any readiness on the part of young people. In one person's case, readiness to leave school and conflict with both the approach and individual teachers and students caused him to leave prior to eighteen and seek out an alternative form of education. For Quinn, Possum and Zac, the transition from school to the next stage had been at some level disconcerting, and it took time for them to adjust to the next stage after school. Quinn missed her school and her friends, and found it hard to adapt to her new environment. She found her TAFE course intimidating, saying

'I'm shy there. If people talk to me in class, I won't even answer. I won't say a word.'

Possum also found the transition from school a big adjustment. Zac was relieved that some of his friends from school came to the same service with him, as it eased the uncertainty, but worried about how other people from school were managing who didn't get support. He had seen a growth and change in himself since leaving school:

'I'm a very sociable person now. I'll be honest, I wasn't a very sociable person last year, I wasn't very sociable. But now I think I broke out of that shell, and I'm comfortable about going out, seeing friends and just having a good time.'

Other transitions young people named as challenging were going into work, moving out of the family home, and moving into adulthood.

Disability and impairment

Everyone involved in the research used disability support services and was recruited to the project on the basis of being a young person with cognitive disability. Recruitment and consent materials were clear about the target group for the research, and this was mentioned to young people as part of the introduction to the project. However, impairment was not discussed by most of people in the research, featuring in no maps and by few people in photos and discussion. The impact of impairment was raised by five young people. A further five people made references to their impairment incidentally while discussing other topics. Where it did appear, it was discussed primarily as a barrier to living a more desired lifestyle, rather than as a part of personal identity, with some important exceptions.

Many young people were sensitive about literacy, and the accessible methods helped defuse tension over this. One young person said

'my biggest challenge with me is that I can't spell or read or write... I can read certain words, but my brain doesn't allow me to process them in the right way. So, it's difficult when you're trying to read something, and you're going like 'what?' And it's like 'nooo!'

Derrick said that at school his class talked about 'can-ability', saying

'disability might just affect other people but can-ability's the best'.

In our mapping interview, he mentioned that sometimes when people

'talk a lot of conversations, I just don't get a lot. And I have to just focus on getting it.'

Health and wellbeing issues associated with particular physical and medical conditions impacted on five people, but only three of them talked about these as affecting the way they viewed themselves. Zac included a photo of a long scar on his arm, which was a success story, as it was a recent operation he had had to have tight tendons released, which gave him more movement in his arm. He also included a photo he captioned 'medication in the morning' to capture his regular daily routine. One person included several photos about how her daily family life is organised around minimising complex epilepsy. For one other young person who uses a wheelchair, managing weight was a constant worry, as they rely on a family member for care who has their own health issues and struggles to lift them. Wayne had included several photos of his doctor, medical supplies on a cart, and his mobility scooter (perhaps at his mum's encouragement). He was not interested in discussing these, choosing to focus on other areas of his life.

Two young people referred to depression, talking about taking medication for this and speaking in the context of trauma and loss. One young person talked about the effect of anxiety in their life, saying they didn't like to spend time alone.

One young person talked about how corrective surgery had seriously set back her physical mobility, and impact that this had on her social participation and the way she felt about herself. She said she doesn't go out much, waiting until her walking improves and then 'I'll go do everything'. While she is gradually improving, it's taken a couple of years, and she is still reliant on other people to get around, needing a wheelchair to go any distance and disliking this:

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.

Two young people in the research had sensory impairments. For one, this impacted on his confidence in social relationships, and he felt that he had little understanding of the social rules that underpin friendship and social relations.

6.

How living in a regional community shapes these experiences

The places, relationships and features of identity discussed in the previous section identified as important by young people were experienced in a regional context. All of the young people in the project lived in regional towns or outside of them, and this was an element of their experience we were keen to explore with them. As part of their photography research, young people were asked to reflect on what it was like to live in their regional town – the facilitators, barriers, people and places that make up their town and how they feel about them [see appendix 2 activity guide for details]. Survey respondents were asked what was good, and not good, about where they lived, and their responses were highly consistent. 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 suburban 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 three of the four young people who lived rurally in the photo research, and by the three survey respondents. Being known in smaller communities is 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.

Figure 6: How regionality shapes young people’s experiences of belonging and connection

PLACE	RELATIONSHIPS	IDENTITY
<ul style="list-style-type: none">• Sense of place• Compared to other places• Regional effects• Transport & travel• Rurality• Nature	<ul style="list-style-type: none">• Being known locally• Reliance on family for support	<ul style="list-style-type: none">• Being regional• Being rural• Impact on agency• Transitions

6.1 Place and regionality

Sense of place

A regional sense of place was important to some people in the research. People talked about living in or out of town, and about feeling a sense of belonging in their town because it was familiar. Ellyse, for example, said she belonged in her town, because she had lived there all her life, and knew her way around. Many people differentiated between their local neighbourhood and 'town', the centre of the town. Angus spoke at length about how important the town clock tower and war memorial were to him. He said it was a town icon, and something he saw almost every day. He said he reflected on the sacrifice made by soldiers in war when he saw the memorial, and liked to take a minute to think about them. This seemed an unusual focus for a young boy, and I wondered if his family had prompted him in preparing for the project, but he maintained a steady interest in this throughout the project. During the research, Angus asked his parents to take him out at night so he could take the exact photo he had in mind.

'I made sure to get a picture of that. I just - it's a big icon in [this town]. It's been here for years and years and years... It's been here ever since I've been born. When I was born thing weren't around. You didn't have DVDs, you didn't have X Box 360 games, you just had Game Cube ones. Things have changed, hey? But not the clock tower? No! That's always been here.'



▲ Bus stop. By John

Compared to other places

Some young people also thought about their town in comparison to other localities. For a small number, this meant comparing their regional town to the city, where they felt more entertainment, excitement and a more dynamic environment would be available. This did not mean that they disliked their town, but rather they liked more the idea of living in the city. Two people had specific future plans to move to the city. Others expressed satisfaction with their current regional lifestyle, and compared one regional place with another. Derrick, when asked if he liked his town, said 'Yeah, it's a fine place.' He went on to compare his town to three other close regional townships with smaller populations, and then said 'Those three towns are alright, but I like [my town] better'. He included a photo he had taken at the town outskirts of the 'welcome to [town]' sign in his photo set, and chose this as a preferred image to exhibit because 'people like to live here in [this town]'.

Regional effects

Most people in this research were living in town, and described patterns of life which reflected suburban living, but with a considerably smaller range of activities and entertainment available to young people, and reduced availability of goods and services. Many young people talked about how there was not a lot to do in their town, and devised ways of making their own entertainment. Shopping featured strongly in the weekly routines of several young women, and four young women talked about how they liked to get to the closest regional city when they could for better shopping. Nikola talked about how her friends tended to come to her place out of town a lot. John Sena went on a round trip on the bus, for the ride. Stacey said her town was 'not always the best place to go out', and went to friend's houses to 'drink and party' in preference to going to some of the town pubs, as she felt safer. Zac mentioned that there was only one live music venue in his town which didn't use lights that triggered his epilepsy.

In all three sites, people described using shared services for support for community participation, and there was a limited range of choice of services for disability support and also in broader education and community engagement arenas. There was limited access to places where young people could be together socially without a service overlay. The closure of two businesses in one community which had been particularly well used by people with disability had been keenly felt by young people in one site, and two years after the closure of the ten pin bowling alley, some people still referred to how much they enjoyed it and how much they missed being involved in the league. For the young person who was same-sex attracted, no queer friendly drop in centres, youth or support services were known to them in their town.

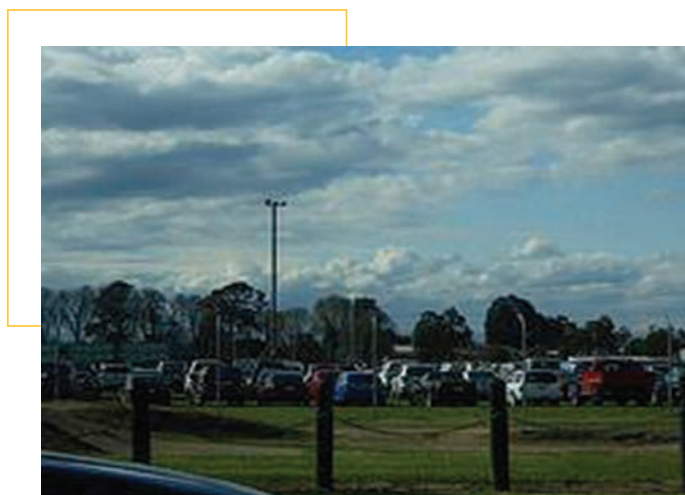
The regions in which two of the sites are located have a lot of heavy industry, and the impacts of this can be seen in and around the towns. It was interesting that little of this is reflected in the photos of young people. Few photos explicitly depicting a negative view of regional living were included by young people. Two young men included photos of rubbish and land degradation, with environmentally oriented captions. The increasing busyness of town was seen as a negative by Matt, who included a photo of the local shopping centre to demonstrate how much he disliked recent renovations, because he could no longer get in and out within five minutes.

Transport and travel

The majority of the young people in this research didn't drive, and family members or taxis provided their main means of transport. Regionality was also evident in the way that many young people spoke about distances when they were talking about travel and transport, particularly in referring to the distances they travelled for specialist medical care (up to eight hundred km), shopping (two to three hours each way to the 'good shops') and for shared parental care (in one person's case, a three hour round trip).

Limited public transport was available in each of the sites, primarily buses. Some people used these to get to and from their disability services, and said they sometimes had trouble with reliability. Buses stopped early in the day and had very limited service on weekends. Seven young people were driving or learning to drive, and those who had their provisional licences and cars had considerably increased independence and a greater diversity of activities in their lives. Nikola, for instance, had a job, was studying, and an active social life and in part this connected to the fact that she could get herself to and from these activities.

While young people were not asked about income or family resources, in several cases it was clear from young people's photos and comments that lack of resources prevented travel, such as visiting larger cities or even some local travel.



◀ *Lots of cars.
I don't like [town] being so busy!*
By Matt

Rurality

Living in the country was described as important by all four young people who lived rurally. For Katie, the bush was an important site. She said that being outside of town was important to her, and she 'hated cities – I really can't stand them' and that open spaces made her happy. Being connected to large animals, particularly horses, as well as pets was an important factor in making country living preferable to town life for three people, and Nikola also liked being surrounded by bush and having few neighbours. Having open space also resonated for Possum, who used the space on his property for construction and mechanical projects, and for Martin, who rode on his bike to watch the long distance tilt train rush by.

Where do you ride your bike?

'Oh, over to the railway, wait for the train to come past. It's boring, riding, too. You sit there, and wait, and you have to wait for when it comes through. Tilt train - I love the tilt train. Sometimes I go too early, and I think 'No! I'm way too early!'



▲ *Dad picks me up each fortnight and takes me to his house. By Katie*

Nature

Natural places featured in the photos of twelve young people, and from their conversation it was clear that nature and being in natural places was important to many of them. Megan included a caption on a photo of flower petals that said

'my heart belongs in nature'

and talked about how connected she feels to nature. At a more domestic level, Cookie and Matt both included photos from their gardens which had a very personal symbolic meaning for them. For Possum, place was very important, and he documented both his home and other natural places with great attention to aesthetics and detail. Yoshi talked with enthusiasm about spending a lot of time in his local creek, catching yabbies.

Survey respondents liked the quiet and slower pace of life in their regional communities. The ease of movement was mentioned by two people, with comments including 'Easy for me to get around. Walk, ride my bike or run.' Two people felt there were lots of things to do in their town, and nominated movies, dancing class, shows, sports and clubs. Carnivals at Christmas and Easter were enjoyed by one person.

Respondents did not like the lack of public transport, the lack of disability access in many places, and the isolation. One school age person commented 'my appointments are out of town, so I miss school'. Another person felt there was not a lot happening if you want to explore. The restriction on personal development was felt keenly by one person, who said 'it's hard for me to have a house so I can live alone. It makes me sad'.



▲ *This shows how long trees in the rainforest grow. I enjoy seeing things in the natural environment. By Possum*

6.2 Relationships in regional towns

The intersection of regionality with the priority relationships of young people with family, friends and support workers can be seen in several ways. Young people described both positive and negative effects of living in a regional town on the relationships they had with others.

Being known locally

Some young people felt a sense of belonging which came through being known in their local communities, by virtue of their small size and geography and the way in which local networks operated. Sam said when he walked down the main street in his village, lots of people said to him 'Hi Sam, how you going?'. Although she lived rurally now, Katie said the village where she had grown up was important to her because she knew 'over half the town when I was there'. Being recognised and seeing people they knew in the streets of the larger towns was important for Sam and John Sena, and photos of people in their loose community networks appeared in their photos. A considerable number of the young people, however, appeared less socially embedded in relationships in their local communities, and did not include photos or discuss relationships with people outside of family, friendship or service networks.

Being part of a smaller community was constraining for some young people. A fundamental reason for this tension was a feeling that people in wider social networks such as ex-schoolmates, neighbours and extended family friends knew too much about them, and made inaccurate judgements based on gossip. For one person this was based in disability discrimination, and for another two in malicious gossip about family trauma. It was hard for these people to keep sensitive information and events private, and they found this very difficult. One person expressed a particular dislike for their town, saying 'Mum and I are out of here. As soon as everything's done and dusted, we're gone! Where are you going to?

'Anywhere apart from [town]!... I just want to get out of here, forever.'

As with the photo research, survey responses were nuanced and included a range of positive, negative and mixed experiences. Several survey respondents liked the increased sense of community they felt, noting 'people are friendly where I live and accept me for who I am'. Having a shared history from school was a positive experience for one person, who talked about how people came up in the street to say hello. Others were more ambivalent, for example one person noted

'everyone knows me - sometimes good and sometimes not'.

For a third person, being known was a negative experience, and they noted

'the schools, the kids and their parents. They gossip and like to spread rumours. No-one really helps you or tries to be your friend.'

Reliance on family for transport

The limited availability of affordable and reliable public transport affected young people's relationships. A considerable proportion of the young people were reliant on family members for transport for any participation, and this meant that the availability, ability and willingness of family members to drive them places was a key determinant in how active their social lives were. Distance also impacted on this, and some young people lived a considerable distance from others with whom they were friendly, making it hard to get together. Living in town mitigated this for the people who could walk or otherwise independently make their way to some locations. Wests Tigers talked about how fond she was of Wayne, referring to him as her boyfriend. When asked if they had been going out together for a long time, the effects of rural living, physical impairment and having to rely on others for transport are clear in her response:

'I haven't been out with him. He lives in town, I live [in locality 25km from town]. He invited me out for his birthday lunch, not last year but the year before, and I couldn't make it because it was raining.'

Some young people in this research also relied on support workers quite substantially for facilitating their social engagement. Some young people used the same services during the week and also for social support on weekends.

6.3 How regionality affects young people's identity

Living in a regional area affected young people's identity in a number of ways. For most people, their regional setting was unremarkable, a backdrop to their daily lives that they had not thought critically about before – it was just their home town. Some people had thought about how they felt about their town or rural location and their place in it. Their direct reflections, and less direct contributions of others about the way that they use place and social networks tell us some interesting things about regionality and rurality as a young person with disability.

Being a regional young person

Young people had mixed and nuanced views about being regional. A small number rejected it, and could not wait to get to a city. They were counting the days until they could leave their town. However, most liked being a regional person, particularly because of the size, ease of moving around and their level of knowledge of their town. Unsurprisingly, young people with wider social networks in their local community were most positive about their towns. They talked about the friendliness of their towns and villages and how they felt known there. There were divided views about the degree to which their towns met their needs, and whether they needed to travel to cities regularly or not. Shopping provides a good example. Young people who shopped for leisure took two distinct views – either that the discount stores were great, or that shopping in the town was very limited, and they needed to travel a distance for 'good' shopping.

Being a rural young person

Some of the young people identified themselves as country people, particularly those who lived on rural properties. Many people identified with the idea of living 'in or out of town', and made a distinction between regional town living and rural living. The open spaces, quieter pace of life and ability to have large pets such as horses was highly valued. Most of the young people who lived out of town also had a closer affinity with nature than people living in the towns.

Milestones are harder to reach

A connection can be made between regionality and agency in the young people's research data. All regional young people may have limits on their social participation, and many feel ambivalence about living in country towns. For these young people, a series of particular tensions and struggles are evident. Being reliant on other people (for transport, support for daily living activities, communication, and so forth), community attitudes to people with disability, discrimination, and the impact of impairment combine to make the lived experience of young people with cognitive disability somewhat more complex.

This tension, in combination with limited resources, makes it harder for some of the young people to reach some of the transitional milestones of 'adulthood' than it might be for their city-based peers. The ones that young people in this research talked about were getting a job in areas of high unemployment, obtaining a drivers licence with limited financial resources to buy and run a car in regions with little public transport, and moving out of home in places where there are few support services for young adults who need assistance. Megan put it well in saying

'I would like to get a job, but it's just finding a job in [town], that's the hard thing to do... As much as I'd love to give my time and volunteer, it's just not something that I'm going to get permanent work out of, and a paying job.'

There are many other goals which are important to people with ranging support needs. Having less opportunity to fulfil these and other life goals not only impacts the agency and personal identity of developing young adults, but continues a high level of reliance on their families.

'This is my dad driving me around. He has started giving me driving lessons so soon I will be more independent. He even taught me how to do a hill start.'



▲ *Dad driving.* By Cookie

This is on the land where I live. By Katie ▼



7.

What promotes and hinders a sense of belonging and connection for young people?

The character and extent of the connections that young people have to places and people give us considerable insight into some of the factors which may help them to feel a secure sense of belonging and connection. This data, combined with the perspectives of the young people about what they feel helps, is used in this section to discuss the things that promote belonging and connection.

A considerable number of factors which promote and constrain belonging and connection emerge from the data, clustered around connectedness, belonging, agency and capability, places that support relationships, and safety. Figure 7 provides a snapshot of the facilitators and barriers which emerged as most important.

Figure 7: Facilitators and barriers to young people's belonging and connection

FACILITATORS

- Family as a foundation
- Depth in friendship
- Mutuality & reciprocity in relationships
- Having a sense of personal agency
- Recognition of capability
- Being understood and valued
- Feeling a sense of alliance with others
- Feeling comfortable
- Feeling relaxed and secure
- Being respected
- Shared regard between young people & support workers
- Sense of place
- Virtual connections
- Supported transitions
- Feeling & being safe

BARRIERS

- Discord in families
- Shallow & limited friendship
- Loneliness
- Struggle in accepting unwanted care
- Lack of authority over decisions
- Feeling like you don't fit in
- Lack of access
- Not having enough to do
- Distance/lack of transport
- Unacknowledged loss & grief
- Violence & abuse

As expected, there was a high degree of resonance between these results and what young people initially thought about the necessary conditions for belonging and connection (see section 4). In some areas, the results extend young people's initial responses, particularly where people with high support needs were not able to tell us, but showed us what mattered to them through their photography. The results extended the concepts of belonging around capability relationships, personal development and recognition of multiple identities.

7.1 Connectedness

Young people's expectations of connections

Family as a foundation

Young people's relationships with their families were a key determinant of belonging and connection, and most young people presented their relationship with family as a foundational one. Where young people described their family relationships as facilitating their sense of belonging and connection, they described or documented mutually supportive and reciprocal relationships in which young people actively contributed to the family. Some people had difficulties and tensions in friendships which increased the importance of family relationships to them.

Several young people talked about home life being difficult due to conflict, loss or loneliness. A third of young people in the research talked about difficulties of one kind or another which negatively affected the way they felt about family relationships. Some of these were conflicts with siblings and parents which were underpinned by what young people described as loving foundations. Other discords were at a more fundamental level (see grief and loss, below). Where young people felt their base of family support was not reliable, their confidence and optimism was affected.

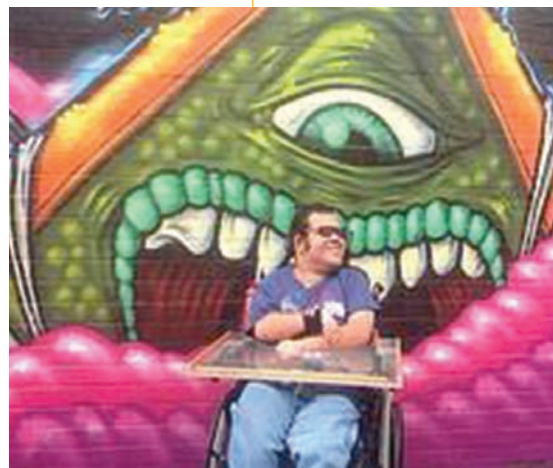
Friends

Friendship was expressed by young people in this research at varying depths. At its most meaningful, young people identified mutual and reciprocal elements in friendship that resourced and supported them. These included having shared interests, appreciating each other, giving to each other, being able and wanting to spend time together, supporting and being supported emotionally, and being able to survive a few bumps in the path. These relationships were expressed through comments such as

'good friends have your back at all times',

'we do lots of things together' and

'we been friends a long time'.



▲ Luke. By John

In many cases, however, the friendships and social connections of young people appeared both shallow and limited. Most of the young people in this research named few outside their families and service networks. The number and location of friends is not an indicator of how well or easily young people make friends, or on the quality of their friendships – many people have small and intimate social networks. However, some young people named friends at least in part based on proximity due to shared service or school use, rather than shared interests, personality traits they liked or experiences shared over time. For people with higher support needs, this was actively encouraged by support workers. In planning and implementing service related activity, while care and attention was paid to individual support and the

development of skills for increasing independence, little evidence of planning for friendship development was observed during the period of this research.

Many young people with lower support needs talked about low-level interpersonal difficulties in their social networks, mostly driven by not having enough to do, gossip and negative commentary on Facebook. These rumbled along as an undercurrent in the relations between young women in particular, referred to as 'drama'.

Loneliness

Many of the young people talked quite openly about their feelings of loneliness, and desire for more friends, and it is present less directly in the commentary of some others, who talk about completing activities with family instead of with preferred friends, watching other young people and wishing to join them but not feeling confident, and feeling geographically isolated. The service lens that is applied to some friendships may also mask some loneliness, as referring to colleagues in services as friends precluded some conversations about friendship from occurring.

Stephen, who attended both mainstream and special schools for part of each week, said he was not as popular at the mainstream school as he was in the special school. Loneliness was also a concern for another young person, who said she found herself sitting on her own a lot, felt left out, and said 'I just don't have any friends'. She had a friend at sport who was important to her. When asked if there were places she would like to go that she doesn't go now, she said she would like to go to her friend's house, and felt excluded from parties and gatherings at this person's house which she wasn't invited to.

One person felt that people avoided speaking to her, misreading the signals that she sent out and thinking that she didn't want to talk, when in fact she would like to. She arranged a photo of herself holding a sign saying 'you can talk to me'. She said

'I just thought that a lot of people should know I'm not the big bad wolf!'

Another who had recently left school said found it hard to get used to new people, and that she feels lonely during the week at the disability service at times. 'I'm used to my normal friends'. One survey participant wrote

'People don't understand me because I look ok, but I can't do most things so they just ignore me. It hurts'.

Another person directly linked loneliness to belonging, saying:

'It's not fun to feel you don't belong. Cause it's like everyone's over here [draws three people's heads close together] **and you're all the way over here** [draws a single head 10 cm away] **with your arms crossed, and it's just like 'why don't I belong?' cause you feel really sad** [draws tears and sad face on the single head]. **And everybody's all smiling and laughing without you** [draws smiling faces on the clustered heads] **and you're all the way over there crying.'**

Mutuality and reciprocity in relationships

Many young people raised the importance to them of recognising that their relationships with family members, friends and support workers are mutual and reciprocal. This emerged from the data in multiple ways – through photographs and captions that showed people providing practical support such as meals and making statements of care for their families, through statements about how they care about their friends and show their concern, and through the depiction of family and friends as people of key importance in the maps of all young people, and support workers in the great majority. When relationships were less reciprocal and mutual, some young people felt disregarded. One survey participant noted 'nobody listens to us', which was reflective of the views of a small number of participants.

Feeling a sense of alliance with others

Having fun with other people, and doing things that were entertaining was important for young people in feeling a sense of belonging and connection. Having a youth focus in the framing of planning and activities was important. Through both daily activities and milestone or significant events, people were very much enlivened in talking about what they enjoyed – it was motivating, uplifting and engaging.

7.2 Belonging

Emotional qualities of young people's social networks

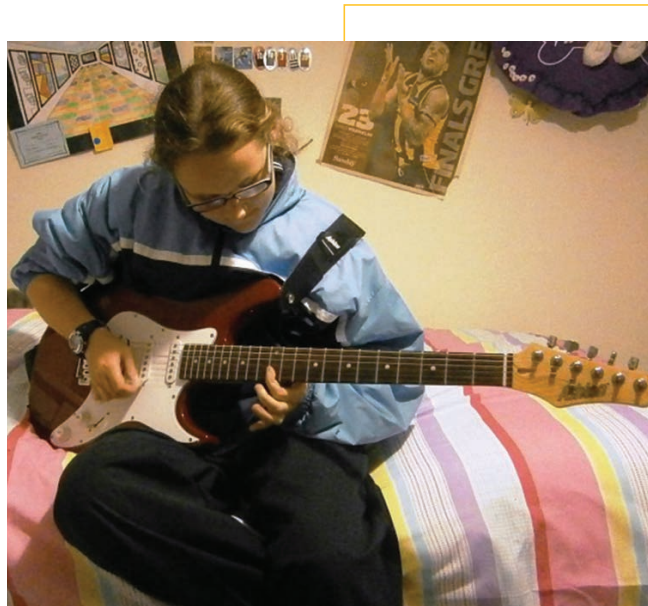
Feeling relaxed, secure and comfortable

Feeling relaxed and secure in relationships was raised by some young people as important as underpinning concepts related to comfort and safety. Feeling comfortable in relationships helped young people to feel relaxed and able to express themselves, and to feel a sense that they would be accepted as they were. Feeling safe supported a sense of security and trust in interpersonal relationships.

Having places where you feel comfortable, relaxed and able to 'be yourself' was nominated as important by some young people in both photographs and interview narratives. Home was the clear stand out place where young people felt this sense of comfortableness, and they also connected feeling comfortable to being at the homes of extended family members and friends and at their disability services.

For some, this was about feeling a sense of fitting in and not standing out. Cookie said 'I belong in this group, and I just mix and get along with people'. For others, it was a sense of alliance with other people, and that a collective understanding about the way that relationships would be conducted was in place and could be relied upon – that private issues discussed in a personal development group would remain in the group, or that support workers would assist to ensure that negative personal interactions between people using the service did not continue without intervention.

Feeling uncomfortable in places was raised by several young people, who talked about avoiding certain places, about not wanting to go to places because they were not well liked there, and feeling like the rules of places (particularly schools) worked against them getting support in the way they needed, particularly around resolving conflict. Standing out was seen as negative by many of the young people, whose experiences of standing out from the crowd had more often been associated with stigma rather than promotion of talent or their other positive qualities. An exception to this was the people involved in playing music, who gained a great deal of pleasure and status from playing in public. For a small number, feeling uncomfortable in place extended to home, where they said they did not feel a strong sense of connection to others.



▲ *I feel happy and relaxed when I play my guitar at home. By Kristen*

Being respected and valued

Being valued and treated with respect in demonstrable ways was clearly important to all people involved in the research. Having capability reinforced and promoted, having interest shown in activities and developing relationships by people who matter, being supported with sensitivity around the need for care, and being positively known in their local communities were all facilitators of belonging and connection for many of these young people. These relationships often crossed formal and informal care boundaries. Wests Tigers was ill at the time of the project exhibition, and bitterly disappointed at the thought of missing the launch. Her support workers galvanised, and went to considerable lengths to ensure she could be part of the evening, consulting with she and her family and arranging a pass-out for the evening with her doctor, and bringing clothing and make up to the hospital, making sure she had support to get ready, providing transport to and from the event, and arranging special entry to the gallery to avoid a large statue which she had a great fear of.

Over a dozen members of her family attended to celebrate her achievement as artist and researcher.

Extended family, particularly grandparents, were important to many young people in supporting a sense of being valued and loved for who they were. Friendship was important in promoting status and feelings of wellbeing. In relationships with support workers, demonstrated respect, embodied through voice and actions, strengths-based support approaches and knowing when to step back was key in young people feeling valued.

Young people provided responses about the impact of disrespect and lack of feeling valued both directly and through the ways that they interacted with others. Megan articulated the strength of her feelings very clearly:

'if you get on my bad side, I'm not going to be a nice person. But if you respect me, and respect my decisions and whatever, then we'll be fine. But I'm not going to take anyone's shit, trying to change me. Go away, basically. Cause I don't want to know you. Respect me for who I am, and don't try to change me.'

Observing the interactions of young people together, with support workers and in the wider community, there were many instances where the (quite justifiable) sensitivity of young people to disrespect could be seen. Meeting new people was stressful for several people, who talked about how they liked what they already knew. Interactions with support workers who were somewhat abrupt or dismissive of the ideas or concerns of young people impacted on their confidence and enthusiasm. Sarcasm from workers was hard for many to understand, and undermining. The responses of young people in these situations were most commonly to withdraw, either physically or emotionally.

Being understood

When there was a degree of accord between the way young people saw themselves and the way that other people related to them, they felt that people understood them and valued them – they felt known in a positive way. Feeling misunderstood and unacknowledged created anger and distress for some young people in this research. A young person who reflected on their unhappiness at school said of their teachers:

'They don't understand people. They don't understand me.'

It was difficult for another young person to maintain a spiritual life which was important to them, as other people in their family didn't prioritise this and they were reliant on transport to get to church. For some people, a lack of acknowledgement of their internal life was evident. One person said

'I'm like an onion - I have layers!'

in conversation about how they feel that many of their deeper insights aren't in view or acknowledged by others.

When the multiple roles, relationships and identities of young people were in view and responded to, belonging and connection was fostered by appreciating the depth and diversity inherent in people and building acceptance. The wide range of personal qualities, preferences, and emphases demonstrated by young people in this research call out for responses which see and understand them in terms wider and more holistic than 'people with cognitive disability'. Like everyone, these young people straddled multiple identities in their lives – as [grown or growing] children, siblings, friends, students, service users, workers, consumers of goods and services, musicians, artists, and now researchers. As well as these evident roles and relationships, some young people talked about the importance of spirituality and creativity in their lives.

While being known was important to young people, a lack of privacy was identified as annoying and intrusive by several young people. Those who talked about this said people in their town knew too much about them and their business, and gossiped about them. One young person talked about how her parents and grandparents knew a lot of people in the town, and as a result, she was much more known than she would like, and didn't feel this was in a positive way. After negative experiences at school, she was glad to leave, but keeps bumping into people from school who 'bring up bad memories'. A respondent to the survey said 'The schools, the kids and their parents. They gossip and like to spread rumours. No-one really tries to help you or be your friend'.

Unacknowledged loss and grief

Serious loss and grief affected many young people in this research. Over a third of the young people talked about particular losses such as deaths or traumatic events – a high proportion, considering that we did not ask them about it. People with high support needs were not able to talk with us about this more abstract topic and it is likely that they have experienced loss and grief too, but we were unable to find out about it.

The deaths of family members clearly affected some young people. For several people, these were grandparents or older family members. Such deaths are quite common in young people's lives, and constitutes an ending or reduction in a relationship or belonging. Other extended family members of three people had also died, one person saying that as well as his grandma, 'my best uncle is dead as well'. One person had lost their mother four years earlier, and this loss continued to have strong impact. For another young person, the recent death of a sibling was a painful and emotional subject, compounded by the death of a grandparent during the course of the research. One young person showed a photo of a memorial plaque recently made for 'a friend of mine at school. I miss him.'

Some family members and support workers expressed surprise at the expression of remembrance by two young people in their exhibition material. For the young people, these acts of remembering people – in one case in the family and in the other symbolically – were important to them and they were firm in their thinking about the need to include them in their photo sets. For some of the other young people, these losses were too private to share more widely and they included images which were symbolic of either the person or the loss, or chose not to include any images. Two young people talked about withdrawing from other people and activities in response to grief from loss, and one person talked about having difficulty in managing anger and frustration.

Other forms of grief were also expressed by some young people. Fracturing of family relationships was a source of distress and grief for some, and young people talked about unreliability from adults, lack of care, and lack of acceptance as causing them pain. The impact of this is clear in the statement by one of these young people:

'I lost the trust in a lot of people, because they kept breaking their promises all the time... I just think my family is a distant family now'.

For some young people, feeling like they do not fit in was a source of serious distress. Three people in particular talked about how painful they find the experience of feeling different and like they do not belong, one saying

'I know what it's like to feel not belonged. Because I feel that way a lot'.

The tensions and struggles with friendship described in this section also have an impact in grief, and some young people talk about how emotionally hard it is for them to feel that they have too few friends or their friendships are not strong.

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'

The pain of loss and grief was clear to see in many of the young people. The impact on their lives was even more serious where young people had not received support, or were not receiving support to come to terms with loss and grief. Four young people talked about events associated with loss and grief which included violence, running away, self-harm and depression.

7.3 Agency and capability

Young people's capabilities

Being recognised as a capable person was very important to most of the young people, particularly to people with high support needs, who were less able to verbally articulate what was important to them.

When young people's capability was not recognised or promoted by others, it both limited their participation and also the ways in which they were viewed by the people close to them and the wider community, increasing their 'client' role and decreasing the number and range of other roles. Possum's extensive mechanical knowledge is an example of this, and several examples of hitherto unknown skills and talents appear in the photographs of young people, such as art photography, musicianship, artistic talent, athletic ability, cooking, gardening and finger-knitting.

Young people's personal agency

Relations of care

Young people in this study did not view themselves as recipients of care, but as active and contributing family members, friends and partners in support relationships. Being an active agent in how relationships are operationalised, in how support is provided, in choice and decision-making on individual issues was important to many young people. This was expressed through photos and commentary about making choices and decisions, being a friend, and having a say about the way the support role was carried out.

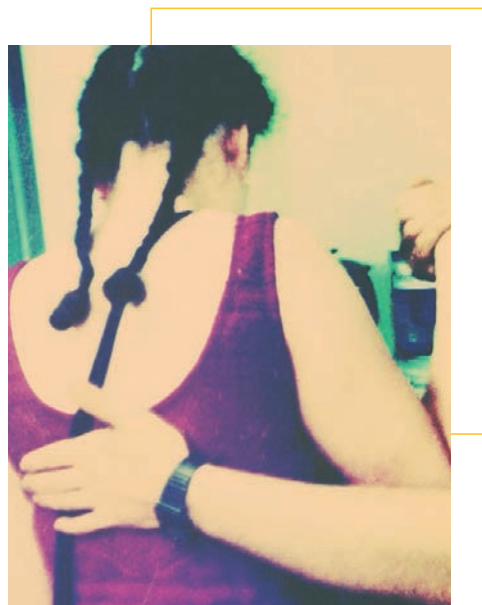
Where young people had the most agency in their relationship with paid support workers, they had a clear conception of the role of their worker, the distinction between worker and friend, and also a close personal connection with their worker – both partners in the interaction had a warm regard for one another. John Sena and Andrew worked together. John Sena said of

Andrew 'he is very friendly, and helps me on my music career'. Andrew said of John Sena, 'for me, this year with John Sena has been about learning to pull back' and learn from watching him take the lead on their joint artistic projects.

Several young people either questioned or struggled with the level of authority they had over choice and decision-making in their lives. This related to both choices and decisions at a routine small-scale routine level and at broader levels about lifestyle and structural issues such as where to live or how to spend their week. During the period of the research, young people primarily talked about and made decisions about small-scale issues rather than larger ones, although some people referred to having made big decisions, such as buying a car, having surgery, and deciding which disability support service to use after school. A few people talked about how the days and number of days a week they participated in disability services or worked was determined by agencies, not by their preference.

Others struggled with the inherent struggle in accepting care that they did not want, particularly at this life stage. One young person was removed from family into the child protection system. A survey respondent talked about the difficulty in negotiating with support workers who provided lacklustre care, resulting in repeated 'outings' to the shops and little personal development. Jums very eloquently raised an ongoing embodied tension about the difficulty in receiving personal assistance as a young woman with disability, saying:

'This is a picture of how I guess I have to be supported. And we called it 'unwanted support' cause I'd rather be independent. So even though I need it, doesn't necessarily mean I want someone there.'



▲ *Unwanted support.* By Jums

Access

Being able to get into places and move safely around them was an obvious but important prerequisite for facilitating a sense of belonging and connection, and some examples of barriers to this were straightforward, such as slippery paths, flashing lights and lack of footpaths. Physical accessibility to community sites was identified by some people with mobility issues in nuanced ways. Wayne's experience showed that access for him was not as simple as removing a step. In a regional town with few lifts, he had little experience in catching them. He had to overcome a significant fear of lifts in order to use the accessible alternative to a large flight of stairs in order to use the local library. John Sena named the games shop in his town as a favourite place. With a step at the door, it was inaccessible to him, but he described how staff brought out what he needed and talked with him in the street. He said he liked it equally well as the alternative store in the shopping centre, which is accessible, but which he needs to get in the car to get to.

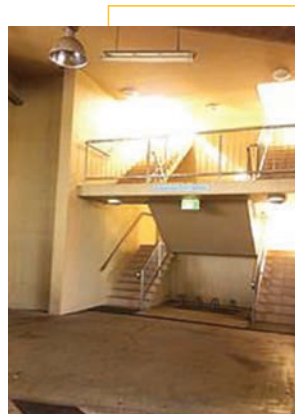
Not having enough to do

Not having enough to do, or having limited places to go which did not have oversight by either support workers or families was raised by people with lower support needs as a limit of regional living. A lack of available work, and unreliable and unstable work of a part-time or voluntary nature was also a feature of many young people's experience. This was a mixed experience, as for some this work also promoted belonging and connection through developing roles and promoting their competence.

Transport and travel

Being able to get around independently was a facilitator of belonging and connection for some young people. The two people who had their provisional drivers licences were working, using a large number of community sites, and going to a wider number of social activities with a range of friends. They said their worlds had opened up when they got their licence, but especially when they got a car. In a regional area with limited and expensive public transport, having a licence was an important step. Both Zac and John Sena talk about using taxis regularly to get to social events and the service. When Leanne started catching the taxi by herself from home to her service, she seemed to enjoy the new autonomy. Sam said he likes catching the bus into town from his village, although he doesn't come to the service during the school holidays, because the bus doesn't run.

Transport and travel was a barrier for some people who relied on others to get from one place to another. Public transport in all three towns was limited after business hours and on weekends. Some people involved in the research also needed support to travel around their town. Living out of town meant that distance, time and expense in petrol was added into the mix for young people and their families when considering whether or not to attend social events or activities.



▲ *I can't use the stairs.*



▶ *I go up in the elevator.*
By Wayne

7.4 Places that support relationships

Access to a range of settings in the local area for relationship development

Many of the facilitators of belonging that young people discussed about place were also connected to relationships. It seems that place is significant because it operates as a site for relationships.

Sense of place

The emphasis on documenting multiple sites, particularly home, disability services, and school and also on internet-connected 'worlds' in young people's photos and narratives showed that many of them have both embodied and virtual senses of place. Most of the young people differentiated between the local and the distant, most often relating this to where extended family lived or where specialist medical services were located. Their sense of place was contained in the local, in the places they frequented and found familiar and comfortable. As well as the key sites named above, these included workplaces, friend's houses (for a few), sporting clubs and facilities, certain cafes and pubs, public libraries, particular parks, and shopping centres.



▲ *[town] War Memorial. Because Australian soldier fought for Australia.* By Angus

Where a sense of place appeared strong for young people, relationships with people in that place were almost always also active and supportive. These sites and relationships accumulated into a sense of place for people. A sense of place was more strongly expressed by some young people than others. Angus, for instance, talked at length about how town monuments such as the war memorial and clock tower held a lot of significance for him, linking him to his town. Almost all of Katie's photos centred on the importance of rural place to her and how it connected to her wellbeing. For young women in particular, a sense of place was connected to the people they felt close to.

Virtual connections

A virtual sense of place was expressed through the ways in which young people were connected via the internet. Facebook and other messaging services, text messaging, YouTube and Google Earth all featured in young people's narratives and photos as important to both their identities and relationships. Some people maintained a similar geographic sense of place, using electronic methods of communication with the same network of people. Others expanded their network to much wider national and global levels, and their sense of virtual place expanded accordingly. Cookie explained the difference:

'Different friends, all over the world. There's some in America, there's some in Italy, one in Mexico. There's this website called Anime Avenue, and I met them all on there, because they're Anime freaks.'

Supported transitions

A few young people talked about the importance of having support at times of transition that helps you build a bridge between one place and the next. A few older young people reflected on school and their transition from school to post-school programs. Quinn and Jasmin both said they loved school, and Quinn in particular talked about how much she missed having her friends around her. They both talked about how difficult school become socially in the later years, but remembered it fondly. Zac talked about how important it was to him that his good mates came with him from school to the same service, as it gave them all some security in a time of change.

Relationships with formal services

Service sites

Several also talked about their disability services as places where they felt relaxed and at ease. This was connected with the people who were in the places (see relationships, below). Zac said

'I like coming here and feeling comfortable with myself'.

One person who had a fairly complex life said

'I just like hanging around here. It's just a good place to come and relax, I gues... I don't have to think about certain other things that are going on, when I'm here'.

Four people who had finished using funded support at one of the services continued to drop in quite frequently, using the computers and having their lunch at the communal table. People with high support needs showed a level of comfort in place, in the level of familiarity and confidence in the use of the physical space – turning music on and off, lying on sofas, using self-regulating strategies (for people with autism) and getting food or drinks for themselves.

Support workers

Relationships with support workers were very important to young people who used a large amount of disability support in services. When these relationships facilitated belonging and connection, from the perspective of young people, one of the features of the relationships was closeness, warmth and mutual regard between workers and young people. Young people

were encouraged and motivated by support workers who they liked, and this influenced their preferences for some activities. In these relationships, the increased depth of mutual knowledge that each of the partners had of the character, preferences and communication styles of the other was evident.

Relationships with teachers were important to younger people, and when they felt known and liked by their teachers, young people talked about feeling supported by their teachers. These relationships were mediated by the school environment – for example, one young person liked her maths teacher in particular, and said she wanted to learn, but found her class so disruptive this was very hard. For two young people, open conflict with teachers and other students made school difficult and a negative place. At the core of their negative feelings about school were feeling misunderstood and disregarded by teachers and other students.

7.5 Safety

Extent of physical dangers in the local environment and availability of protective mechanisms

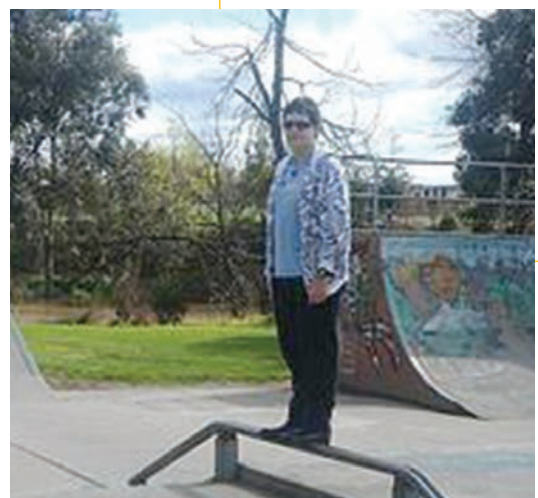
Feeling safe was important at physical, social and emotional levels. Physical safety was important to several young people with mobility difficulties, who included photos of places and situations which posed risks to them and talked about feeling unsafe when their environment was slippery or unstable. A level of risk was seen as acceptable and appropriate to some young people, who were either strongly drawn to risky activities (such as spending time on the streets at night or catching scorpions), or who were impatient at what they viewed as ‘fussing’ by others when they had minor altercations or accidents, seeing them as part of their daily lived experience and wishing to avoid the embarrassment of extra attention.



▲ *Fallen beauty.* By Jums

Extent of human threats in the local environment and availability of protective mechanisms

A few young people in the research talked about restricting the places they used, out of a fear of the people who might be in them. For a small number of people, this was in response to having experienced harm. For others, it related to a fear of harm. Derrick loved skateboarding, and called himself a ‘regular’ skater, ‘just like Tony Hawke, Ryan Shackler, Rodney Mullen and Chad Muska and all those famous skaters’. He says he has only been once to the skate park, because ‘sometimes they say really mean people around’. The time he went, there were ‘nice people just around’, but he remains uncertain about going, and practices his moves in the driveway.



▲ *Good to go when no-one is there.*
By Derrick

Safety strategies

Some young people had strategies to help feel and be safe. More independent young people adjusted the places they went to make sure they felt safer. Certain pubs and nightclubs were preferred by the young people who went out independently at night, as the staff and environment were more welcoming. Three people talked about going to friend's homes rather than out at night. This is also a reflection on regional living, where the number and variety of options for night time entertainment are limited. G1 Joe spent a lot of time on the streets, but only in a group of friends, and he said they looked out for each other. Two people who had experienced violence or negative experiences had a reduced number of places they felt safe (see next section). Young people who were more reliant on support in their daily lives had less control over the places they went overall, although they sometimes had some capacity to adjust the places they went as part of program activities (for example, preferring the library over the park). A consequence of this was that they were less able to learn and use strategies to make places feel more or less safe.

Violence and abuse

Five young people talked about experiences of violence and abuse in their lives.

One woman talked about being physically assaulted in the street. She was punched in the face by someone she knew, and while the police were involved, no charges were expected to be laid. She said she found it very frightening, and was somewhat comforted by the fact that her boyfriend was there, saying it would have been worse had she been alone.

Family violence was described by one young person, who talked about protecting other family members and the fear and distress that they all felt. One young person was removed from their family by authorities during the period of the research and placed first into an informal fostering arrangement, and then when this broke down to a youth refuge. While they did not talk directly about the experience of the breakdown of care, their photos and narrative were angry and distressed.

Two people had initiated violence. One talked about how they regretted their role in 'bashing kids', reflecting on how they felt they reacted in response to feeling agitated and frustrated.

These are very delicate issues. The private nature of some trauma, and recovering and dealing with abuse and harm also needs to be respected, and some disability services did not know much (or anything) about the harms that were related by several people in this study. That is their right, and there are good reasons why they did not want to share this information.

Young people need acknowledgement, support and care not only in responding to harm, but also in recovering from it. It is important that they are able to take the lead on who knows about their circumstances (where this is safe for them), and have control over where they seek support. This was not the case for several young people, who were lacking in support to cope with serious harms. The impact on them was substantial, leaving one fearful, another two angry and a fourth anxious.



Learning about young people's participation in research

In this section of the results we focus on how the different elements of the research design and process supported and constrained young people's participation. The perspectives of support workers who facilitated the participation of young people in the three sites are added to the young people's views and our research reflections. Figure 8 below summarises facilitators and constraints to young people's participation in this research.

Figure 8: key insights about young people's participation in research

FACILITATORS

- Positive research relationship
- Repeat visits
- Developmental project
- Accessible methods
- Guides for supporters
- Guides for young people
- Support by well-known people
- Peer support
- Promoting results in public
- Adapting to young people's suggestions
- Usefulness of methods for practice

CONSTRAINTS

- Low expectations
- Hard to refuse consent for some
- Balance btw direction & support
- Complex method to implement
- Distance
- Irregular meeting
- Group photo research for some
- Survey – reliance on writing
- Survey – reliance on third parties for promotion
- Resource intensive

8.1 Expectation of participation

Young people had relatively few expectations of participation in the research, and nobody said they had been involved in research before. Six people had support needs such that it would not be reasonable to expect them to have abstract forward knowledge about the project. Of the remaining twenty two people who completed mapping interviews, when asked what they thought might happen in the project, many said they didn't know, although they had received accessible information and consent materials and we had spoken about the project in brief terms as part of the consent process prior to the interview. A few talked about taking photos, and four had a detailed knowledge of what they thought would be involved.

Some people talked about participating in the research for reasons other than interest in the topic or wanting to contribute to it, such as having come because their parents suggested they might enjoy it or because they knew the respite weekend camps were fun. Ellyse focused on the relationship possibilities in the project, saying she knew it was about taking photos so that

'people know what you're like. Get to know you better'.

Angus was enthusiastic about the possible opportunities in the project, saying he thought it would be 'hopefully really good' and that

'It may be the first time I can share about the world'.

Two people described the project aim clearly, Cookie also adding a comment indicating she understood her right to privacy, saying she knew that

'that you will have the thing [recorder] on and they said that you don't have to have it on if you don't want to. And if you want to keep it private, you can.'

Gemma said

'I saw a booklet about you at home. And sheets of paper about the course starting. I went through it with Mum'.

Support workers and the project facilitators had moderate expectations of the research, and were attracted by the photographic methods. Workers involved with the project were committed and enthusiastic in two sites in particular, and asked interested and probing questions in the briefing workshops. There was a level of hesitancy about the participation of some people with higher support needs and the research contribution they might be able to make. In interviews, workers said they felt like they had sufficient information through the briefing workshops, resource folder and availability of researcher by phone to support young people as the project started.

8.2 Experience of participation

The research approach provided young people with a supported process in which they had a choice of multiple accessible methods to express what was important in their lives.

Making repeat visits to the sites was important. From the research perspective, this was to establish rapport, build some trust and form relationships. From the perspective of the young people, it was important for the primary researcher to hang around in each place for a while, so that they could establish what kind of person I was – not a staff member or a parent (of them), someone who was in their corner, prepared to play a game, and someone who was genuinely interested in hearing about their perspectives and experiences. In the site closest to the researchers, the ability to travel more frequently to visit the young people made a difference to four people, who were more closely engaged over the project course as an additional three visits to encourage progress were possible.

Support at sites

The three organisations planned in accordance with their expectations of the young people's participation. In site one, this involved recruiting an existing project coordinator to the project facilitator role, using existing casual support staff for the camp and workshops, and using office administration staff to assist young people in uploading photos onto Flickr and with some workshop activities. In site two, the facilitation role was shared between the project coordinator, who took on the practical support coordination for young people, and her team leader, who took a logistical organising role, buying resources, organising the exhibition, and so on. Support workers who usually worked with the young people assisted them where necessary in taking photos. In site three, an existing team leader took on the project facilitator role, and three support workers who knew young people well took responsibility for supporting them through this project.

The amount of staffing resources and the level of skill of staff allocated to the project made a difference to the support provided to the young people. The most crucial facilitator of effective support for young people, however, was interest in the project by support workers and project facilitators. The support workers who were engaged, interested and open to the philosophical approach of the research gave young people real 'lift-off' with their research. Project facilitators who took a similar approach smoothed the path for young people, ensuring they had access to equipment and the activity guides, they understood the material, they were supported if needed, and that the exhibitions were well organised.

When this happened with less rigour, the results could be seen in young people's participation. For young people who were less consistently supported, it was harder to remain connected to the purpose and intention of the research. For example, in site one, staff cut corners with the briefing workshop, prioritising instead the organising of logistics. This resulted in them having an inadequate understanding of the project underpinnings, and they struggled at times to explain the project to young people, as their own understanding of it was limited. For the young people, this reduced the depth and quality of participation. In sites one and two, a group approach to service provision at times prevailed, and this could sometimes be seen in the photos and captions of the young people, and in the opportunities they had to take photos of things that were important in their lives.

Mapping

In the mapping interviews, a substantial amount of information was shared by young people about the places and people important to them and for many, the significance of these in their lives. Young people were gracious and forthcoming in the interviews, and all shared personal information about their lives which enriched the research. It was important that we had several approaches to mapping to meet the preferences and communication needs of the diverse range of people participating in the project. Some people wrote their maps in words, some used a combination of words and pictures, some only pictures, and some used pictograms for key concepts. The more support people needed with communication, the more beneficial it was to have the assistance of a known and trusted support worker in the interview. However, clear briefing prior to the interviews and some reframing of questions in the interviews was important to distinguish a clear support role from a participation role for support workers.

Maps, and later the photo collages, were an immediate visual way to demonstrate clearly to young people that we understood what they were saying, that it was important to them, and that we respected it. Using visual and accessible methods also helped us to 'member check' the data with young people, most of whom would not have been able to read transcripts, and would have been unlikely to want their family to read them on their behalf.

As well as being valuable research data, the maps gave young people concrete reference points from which to start their own photographic research. People with higher support needs were more likely to keep their maps, and referred back to them during the course of

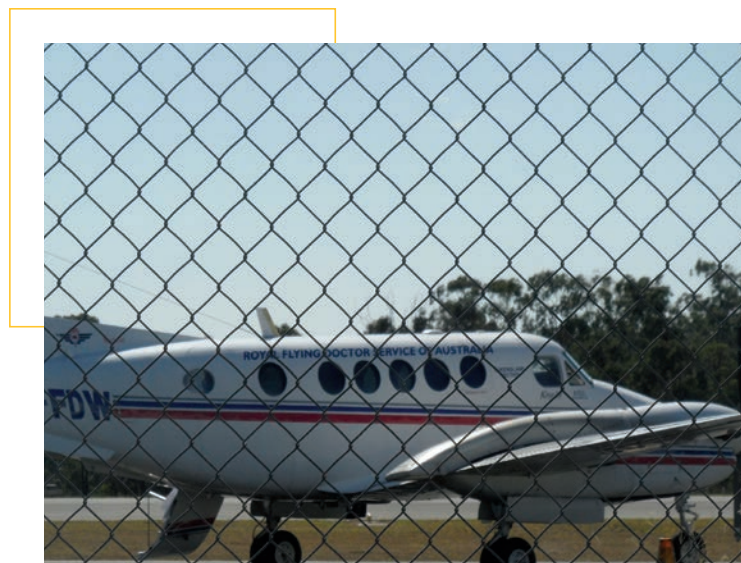
the project. Some people also showed them to support workers and family members. People with lower support needs were less likely to keep their maps, preferring to leave them with the researcher. While engaged in the process, they were less interested in the map as an output of the research, and some were sensitive to any activity, such as putting a sticker on the most important person and/or place, that could be construed as childish.

Photographic research

Photography proved an excellent medium to show connection to both place and people for these young people. This was particularly the case for people with high support needs, who were less able to articulate this connection in words, and was also how they showed their capability in different situations.

The developmental nature of the photographic project worked well for young people who had regular, well-informed and resourced support. The role of support workers was pivotal, particularly for people who received more support in their daily lives. Support workers provided practical support, transport, ideas, reassurance, reminders about the project aims and process, assistance with uploading photos onto Flickr, and help to understand the research rationale. Thoughtful considered support provided to young people enabled them to understand and express the project goal – to share their perspective on the people and places that give them a sense of belonging and connection. A small number of young people initiated direct connection with the researcher to upload their photographs, preferring to communicate via text message and receive immediate feedback on their work.

Some of the photos seemed to show when young people were less engaged in activities, and when ideas might have come more from support workers. Where young people included and commented on photos which were part of organised group or program activity, it often appeared more difficult for them to provide a rationale about its meaning to them. A strong theme in these photos was that young people were 'going with the flow' of what had been organised by services and documenting this activity, rather than seeking to record a relationship or place of meaning to them. Captions in photos sometimes reflected this, particularly for people who needed help in articulating their experiences, and captions were phrased in programmatic language. This changed over time as the project meaning became clearer (and better explained), and the words of people themselves emerged. Two captions were provided for Bradley's photo, below, which articulate this point. The first was written for him, and in the second, his words scribed for him.



Bradley enjoys taking a trip to the airport to watch the planes coming and going.

By Bradley (& support worker).

Big plane, I go on a plane, I go see Max. By Bradley

Some young people also supported each other in thinking about what they wanted to share about their lives, and how they would show this. In some cases, the combination of this creative thinking with sensitive and non-directive assistance from support workers led to very reflective and meaningful research. For example, Zac and Jums worked together over several weeks, thinking about how people saw them (leading to photos of a range of things, like identifiers such as glasses, bracelets and the way people walk, and discussion of what people don't see). In several cases, young people documented their relationships and the activities they did together as a way of reporting facilitators of belonging and connection.

Using the activity guides to either focus thinking or stimulate ideas about possible photos to take was mentioned by both young people and support workers as important as the project moved into the middle stages and it had been some weeks since the belonging workshops and interviews (refer to Appendix 2 for detail). The activity guides were particularly useful for several young people who used them with some support. Jums said

'I think they were helpful, cause I like to be, not told, but just to have an idea of what someone wants you to do. I find it easier, having a guide to help me.'

Support workers talked about preparing ahead of time, so that activity sheets were ready for people to view and think about at the start of the day, or photo session. All workers said they were useful for prompting thinking without being directive, and keeping the project focused. One worker, Andrew said

'I thought the information was presented in a way that kind of invited the participants in without leading them into a particular outcome or involvement in the project.'

People who were posted the activity guides did not appear to get the same degree of benefit from them – the young people in site one, who received them between workshops, said they helped 'a bit' or 'sometimes', but did not say they found them especially helpful. Workers also used the guides as prompts when helping the young people to upload their photos, in one case pre-categorising the photos into people, my town, a day in my life and so on in order to deal with time constraints, and then asking people the prompt questions on the sheets to stimulate captions. This was a more formalised approach to the use of the sheets than intended, but avoided closed or leading questions.

Analysis interviews

All thirty young people analysed their photographic data. The combination of having their research based in their lived experience, centred on the things that are of core importance to them, and expressed in photographic form really seemed to help motivate and engage people. In the analysis interviews, this meant that people were experts on the subject and could speak with authority and confidence about the topic, they had inside knowledge to share, and the method for sharing it was accessible to them. That did not mean, however, that the process was necessarily easy for them. Some people commented that it was hard to make decisions about which of these images told the best story about belonging. Derrick said

'it was really hard. I had to be an expert to think.'

Selecting which images were not important was comparatively easy for most people. Choosing between images which both had some importance was much harder. Some people with higher support needs got stuck in their choice making, and became worried about how to make the best choices. Here, support workers helped a great deal, using their knowledge of the person to problem solve and finding creative ways to acknowledge the importance of all the photos, while working out which one(s) had higher priority. They came up with strategies such as making photo scrapbooks later with the leftover photos, and for people who really struggled with choice, reducing extraneous photos before the interview. While the tone and

process of the interviews were positive and supportive, some people were really tired by the end of their interviews, and several people took breaks after selecting their images and before the final stage of writing their statement for their collage. However, at the end of the interview, people were very satisfied with the outcomes. Looking at her collage, Leanne said in satisfied and emphatic tone

'it's very, very good. Ok.'

Simon's analysis interview was a very different experience to his mapping interview, where he had been tired and quite hard to interest. His photo set had been winnowed down prior to the interview (e.g. multiple pictures of the same scene removed), and his support worker had checked to make sure no pictures that she thought would be really important to Simon had been removed. The photos were placed in front of Simon one at a time, and he named the content of each with interest. Following this, sets of three photos were placed in front of him. As long as the categories were clear (cooking, washing the car, big things), he unerringly scanned across the three and chose his preferred image. Non-preferred images were pushed aside, with a 'go away!' He chose two very distinct favourites, which were blown up as large images in the exhibition. This was very exciting for him to see at the art gallery, as he hadn't made the connection between the photocopies and the exhibition.

Exhibitions

Promoting the young people's work as researchers and artists in public exhibitions in each site was the final activity in each of the projects. This proved a highly validating experience for the majority of the young people. On advice from young people in the first site to hold their exhibition, we spoke about the work of each artist individually in speeches at the launch events, focusing on what the key research message was arising from their work, and what we had learned from them. Each event received media coverage, and young people and their work were featured in local print, radio and television. Many other young people who came to the exhibitions commented to managers and support workers that they would like to do this too, should the opportunity arise. Young people kept their exhibition material – a large collage and two printed images – as owners of the works, and in thanks for their contribution to the project. Early discussion about the possibility of young people selling their work was not pursued due to logistical difficulties, but the funding contract for the research had been negotiated so that young people own the copyright in their own works.



Exhibition launches

Website

On the suggestion of some of the young people, a website has been established to profile their photography. Some young people wanted to see the work of people in the other sites, and the idea grew from here. A consent process was established which invited all young people in the project to consider what publishing on the internet means, and to consent (or not) to the publication of each image they exhibited. At the time of writing, twenty of the young people have decided to publish their photographs on the website. The website can be viewed at www.belonging.net.au

Survey

Usable responses to the survey were received by twenty six people. It was widely distributed through disability and youth network and advocacy organisations operating at a national level, and a somewhat higher return rate had been anticipated. Some of the survey questions asked people about the experience of completing the survey.

A moving face which provided a five point sliding scale was included with a question asking people how they felt about answering the questions. 70% of respondents were either satisfied or very satisfied about answering the questions. 12% were neutral, and 18% were somewhat dissatisfied. Comments indicated that people found the amount of typing required for the qualitative responses onerous, and some of the words 'a bit tricky'. Two people commented that they were expecting a multiple choice survey. Eleven people said they received help to complete the survey, nine from their mums and two from support workers. People helped by typing the responses and in understanding the questions. A range of approaches were described here –

'I got a bit of help at the end. I got a bit of help when reading the questions'

'Mum assist me to understand why you want to ask me these questions'

'My Mum she helped me type and think of answers'

Implications arising from this are that less reliance should be placed on qualitative responses, and increased attention paid to creative approaches to non- or minimal-text options. Embedded videos were investigated in the design phase, but difficult to implement due to the unreliability of fast internet speeds for video download in regional areas. This should be further investigated in future survey design.

8.3 Perceived value of the research approach for young people's participation

A high level of satisfaction was expressed by young people in their participation in the research while it was ongoing and at its conclusion. Some young people talked about what it had been like for them to be involved in the research. A common theme was that the project provided an interesting activity for young people who were looking for additional interests. Ellyse said 'Really fun. It's given me something to do, because I haven't had very much homework lately'. A shared view among people with low support needs was that taking photos was fun, but it was hard to balance the needs of the project in their busy lives. All of the young people, and particularly people with higher support needs, seemed to gain a great deal of pleasure from seeing photos of themselves in a public place and being congratulated on their work. Young people seemed gratified that we had learned from their experience and knowledge, and it was important to explicitly acknowledge this and great that the project allowed a public opportunity to do so.

For some young people, an advocacy effect occurred as a result of some of their photos. The preferences and ambitions of the young people were promoted to those close to them as a result of the project. In some cases these were generalised, in others a new way to express specific needs. Zac exhibited a series of photos of himself which showed what it feels like for him to get in and out of a car used by his service which makes him feel unsafe and at risk of falling. A benefit of this for him was that lots of people asked him about this collage, and he no longer travels in this car.



▲ *Getting into the car. By Zac*

For several sets of young people, the project built relationships, or found a new expression for existing relationships. This included the collaborative creative partnership described above, a growing collegial relationship between two people when they shared another service activity, and a developing friendship between two young men previously known to one another, but who came together in this project as it progressed.

Support workers consistently viewed the project in positive terms, and felt that numerous benefits had arisen as a result of the involvement of both young people and their organisations in the research. On a personal level, they felt young people had enjoyed the project activities and many of them had experienced some personal growth as a result of their involvement in the project. Andrew said, of the young man he supported

'just seeing him relate to the other guys in the project... I think [his] sense of belonging was really boosted by that, because everyone knows him at [service] and knows he's kind of a big personality, but it just sort of opened up a different side to him'.

All support workers interviewed expressed respect, admiration and some surprise at the degree to which many people engaged in the research and were able to articulate what was important in their lives. This was particularly the case for people with high support needs. Kylie said she saw people make connection to the project aims at a range of levels – she felt some people did not make a conceptual link, but she was surprised at the depth of understanding and response of others:

'Leanne really surprised me. I have never seen her so engaged and talking like that... She knew everything, she knew what her stories were and it was like 'wow!''

Six of seven support workers talked about ways in which their perceptions of the young people they support have been affected as a result of watching their involvement in the project. A number said they appreciated getting an insight into people's lives outside of their 'service lives' and felt that had gotten to know them better as a result. Yana's perceptions of the importance of friends and relationships in young people's lives were validated, and she said the project 'made me see how capable they are. They were jolly good photos. And they got it, they got the project.'

Chris said:

'you become slightly myopic, I suppose and you think 'oh, I know what these people...What people that we work with think and what they're thinking about and what certain things mean and then you get the opportunity to truly understand it from a different perspective and it is so grounding that it just brings you back to yourself and you go 'no, you don't actually know'''

Support workers also identified the importance of the research methods for practice and policy. All talked about finding ways to adapt useful parts of the method into their work practice, particularly the use of photography for helping people to express what is important to them. They found the direct communication with the lead researcher to be important in making the project run smoothly, particularly given the complexity of the methods. All thought it essential that researchers with expertise in working with people with disability had a major role in the project, combined with a focus on the development of relationships. Two support workers who also managed other projects linked the project process and outcomes to individualised support, one in terms of the work happening in the organisation to support local choice making and one emphasising the importance of relationships to young people in organising formal support.

The survey extended and confirmed the results of the photo research process, and allowed us to test the applicability of a qualitatively focused survey with people with intellectual disability. The learning through the design of this survey will enable the development of future surveys which incorporate the feedback received from young people about including a higher proportion of multiple choice options, less typing, and maintaining and increasing interactive features.

8.4 Perceived limits of the research approach for young people's participation

While it was important for young people to be able to refuse consent, either to participating in the research at all, or to elements of it, in practice this was not easy for them at times. Consent by the young people was freely given in all but three cases, and supported by consent by parents and guardians where young people were under eighteen or their capacity to give informed consent in any question. Most young people gave their consent lightly, appearing unconcerned about signing the form and disinterested in the details. We refreshed consent on each meeting, and continually watched for assent in people's comments and behaviour. Each of the three circumstances where consent was more complex were different and interesting.

In the first, one young person said very clearly he did not want to participate, although his parents had signed a consent form. The support workers continued to encourage him quite strongly to have a mapping interview, saying it would be 'good for him' to be involved, and I interceded on some occasions so that the young man could continue the activities but not participate in the research. In the second instance, a young person began with a negative perspective about the research, asking whether he had to do it. Simultaneously, I said 'no' and service provider 'yes'. After explaining that this research is all about choice and all the control of the choices were with him, he decided he wanted to give it a try. In the interview, his consent was refreshed and assent carefully monitored. At the group workshop following the mapping process, he said he had something to say: 'this wasn't nearly as shit as I thought it was going to be!'. He went on to contribute in a very important way in the project and to be one of its biggest advocates with the other young people. In the third instance, a young man with high support needs indicated through behaviour that he was not enjoying his involvement in the project. He completed most of his mapping interview, but was very difficult to engage. When he did not enjoy the photography after two or three attempts and this seemed to cause him agitation, together with his support worker we deemed this a withdrawal of consent to be involved and he withdrew from the project.

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. Andrew said

'it was nice to have something where the guys can take the lead and I feel like a proper support or assistant'.

The established working approaches of individual workers and the ethos of the organisations influenced the way that workers engaged with young people. In most cases, relations between support workers and young people were respectful and supportive of their agency. However, in several cases, assumptions were made that young people would not manage without direction. One young person twice refused the offer of a support person for their mapping interview, saying 'I'll be right' with just the researcher. We stepped in to support their decision when the support worker said 'but I've been allocated to sit in with you'. The briefing meetings and workshops with support workers were important in establishing the role of supporters in the project. This was shaped and modelled in the interviews, and underlined with the distribution of the activity guides, which included reference to how young people might use support and the questions which might elicit information in non-leading ways. All of these gave concrete reference points for workers, and for the researchers to refer to when asking for young people's participation to be prioritised (for example, for their own words to be used in captions). These are all examples of efforts to create a hermeneutic ethical environment – where the responsibility for making sure research is ethical does not rest with the young person. The physical distance of the academic researchers from the co-researchers was a clear limitation to the implementation of some of these strategies.

For several young people, it was confronting to think about some parts of their lives. As is shown in section four, loss and grief impacted many young people in this research. Loneliness and isolation was either named or an undercurrent in the work and narratives of some young people. These are sensitive and difficult domains in young people's lives, and while we were privileged to have insight into these important perspectives, concerns about the wellbeing of young people who might be affected by talking, documenting or thinking about these difficult areas were paramount. We checked in regularly with young people who talked about particularly sensitive issues, both directly and through their trusted networks. No young people took up the offer of counselling which was available to anyone distressed as part of their participation in the research. Both directly and indirectly, we were told that while confronted, young people were not traumatised by confronting these issues, and these are things that are already in their lives. Three people said it was good to talk about them.

The widely ranging level of support needs of young people involved in the project meant that it was not practicable to ask many people to review their experience of participation six months after the project conclusion, as had been intended when we originally designed the project. We had established with reasonable certainty in the first two rounds of interviews that people were not looking forward or back with a great deal of reflection about participation. In keeping with participatory methods, the research design was altered reflexively in response to the diversity of participants, emerging data and available opportunities. We decided, in consultation with the sites, that it would be of more value to the young people and their communities to return with the final report, plain English summary and website and report to them completely on the research outcomes than to report on emerging findings and conduct a consultation which we suspected would be shallow and not add noticeably to the research findings.

The complexity of the method also meant that we did not proceed with our original intention to involve people with cognitive disability in a more traditional advisory structure, through the NSW Council for Intellectual Disability Speak Out, Reach Out (SORO) committee. While the research proposal was written with the expectation that people with disability would advise the researchers through this committee, the realities of the high level of demand on this group from other areas, the volume and complexity of detail required for the research method, and distance between the group and the primary researcher combined to make this strategy unmanageable. We adjusted, moving to a capacity building approach where SORO members would participate in the final seminars to both demonstrate leadership to young people and seed advocacy development in the young people and regions. Again, this proved unworkable due to the time resources required to develop and support people to contribute with meaning and the distance between research team and committee. Key members of the SORO committee advised on core elements of the method in an informal capacity, with the support of a participation work with expert skills, who also contributed as a participation worker.

Instead of a committee-based approach, once the groups were established we emphasised consultation with the young people in the project about all of the resources, methods and changes or additions to the research design. Key activities young people advised on included the website development, piloting of the survey, and development of the easy English activity sheets and final report.

Promotion of the survey through disability and youth network and advocacy groups also means that a set of gatekeepers determine the appropriateness of the survey for use before people with disability have the opportunity to make the decision themselves. We have no way to know how many people with disability saw the survey and decided whether or not to participate. However, the survey received few 'no' hits on the proceed button built in as a consent mechanism. The survey design, weighted towards qualitative responses, may have precluded the involvement of some people who did not have supporters to type for them and who were not able to type responses themselves. Future survey development could occur in partnership with expert survey designers to increase the user appeal and interactive nature of the tool, at the same time making it accessible to a wider audience.

Finally, while the benefits of the project have been substantial, the resources required to conduct a research project of this nature were somewhat greater than those provided through the (much appreciated) funding. The organisations received \$4,000 to offset their costs of contribution, and two of them felt this adequately covered any additional expenses, although they provided considerable in-kind support. The third felt the project cost the organisation approximately \$1,500 to implement. The lead researcher conducted the project in part through a post-doctoral fellowship, and this supported a considerable part of the research costs.

9.

Implications for promoting belonging and connection for young people, policy and practice

PARTICIPATION

- It is important to young people that their capability and agency is recognised
- Young people have multiple identities – this needs to be recognised
- Relationships are critical for establishing and sustaining young people's sense of belonging and connection
- Being known and valued is a core requirement for a secure sense of belonging and personal identity

POLICY

- The importance of rights-based support cannot be understated
- Support needs to focus on relationship development as a priority
- Education and training for young people and supporters in relationship building is needed to give this a skill base
- A dual focus on individual young people as well as groups and communities is needed
- Skilled support by those with expertise in youth-oriented environments is important for identity formation
- Virtual connections matter to young people, and should be explored further for connecting young people and for disseminating information
- Violence and interpersonal harm damage belonging and connection. They are pervasive and poorly responded to. Action is needed in prevention, minimisation, response and recovery
- Grief and loss potentially impair belonging and connection. Sensitive support to acknowledge and address loss is needed for young people

COMMUNITIES

- Place is a foundational site for relationships, and where people feel unwelcome or unsafe, they avoid going.
- Relationships in communities are the major determinant of how young people feel about their town
- Living in regional towns can make it harder to meet transition milestones

RESEARCH

- Accessible methods supported young people to share rich and deep understanding, and should be used again
- New practical and conceptual knowledge about belonging and connection emerged, and needs further testing
- The high rates of negative experiences in young people's lives warrant further exploration as a matter of priority
- More research is needed to see how this work might extend or modify theories about recognition, identity, networks, social inclusion and disability

Figure 9: implications for young people, policy and practice

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 understanding and for action. They are useful for practitioners, policy makers and researchers as well for people in the wider community interested in promoting young people's belonging and inclusion. Each provides information and suggestions for action, and is framed according to its primary relevance – for young people, systems and policy, communities, or research. However, there is considerable overlap between categories. Implications particularly important to young people are prioritised in the accompanying plain English report.

9.1 Implications for understanding of young people's belonging and connection

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 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.

The research identified what belonging and connection means with some of the young people, and confirmed and extended this understanding with all of the young people through the methods. The ways in which young people in this research understood belonging and connection resonated with established conceptualisations, but with some important distinctions.

Young people's knowledge was confirmed by exploring their original definitions through the use of innovative methods which also included young people with higher support needs.

This group was not able to answer questions about belonging, but demonstrated to us what was important to them through their photography and narratives, and this was consistent with what other young people said about belonging. In talking about the things that help them to feel included, people also talked about the converse of belonging – the factors that impede belonging and connection such as loneliness, feeling different or trouble with friendships. New understanding emerged particularly about the things that hinder and the absences that impede young people's sense of belonging and connection.

Young people in this research who had a strong sense of belonging and connection shared some qualities. They were well and widely known, and were engaging and likeable people. They were involved in support relationships which were respectful, valuing and promoted their capability. Through the activities and relationships they engaged in, capacity was built individually for them, for community members they came to know, and for their wider neighbourhoods and community through the resulting diverse fabric of valued citizenship. This appears a combination of being personally easy to know, being supported with skill and relational respect, and living in a receptive community. There are critical and difficult questions about how to build or establish a sense of belonging and connection for young people who are missing one or more of these dimensions.

Arising from the conceptions of belonging and connection laid out by young people at the start of this project, and building from this experience, we make an attempt here to identify necessary conditions for a secure sense of belonging and connection. They are consistent with – but extend – the conditions for belonging which form the basis of belonging scales developed by psychologists for measuring belonging in schools, including for students with disability

(Goodenow, 1993; Frederickson et al., 2007). A similar emphasis on capability, being valued, supported, known, feeling like you fit in, and included and accepted was evident. For these young people, there was an increased emphasis on feeling comfortable, safe, respected and on understanding and being understood. The data revealed some areas in young people's lives where it is difficult for them to feel uncritically accepted or included without tension or struggle at some level. A notable absence from the initial work of the young people, but reflected in their photographic work and in observing them together, was the importance of happiness and fun in feeling a sense of both belonging and connection.

Dimensions of secure belonging and connection

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

In order to understand and better facilitate belonging and connection for young people with cognitive disability, an approach is needed which recognises young people's multiple identities. This means appreciating that 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. Young people in this research were diverse in many ways, and had complex and multi-faceted identities. The diversity of the young people in this study is not representative, but it is demonstrative of young people's wide ranging differences across place and space.

Using agency in relationships and places is important to young people in developing and maintaining a sense of belonging and connection. Young people are embedded in a range of roles and relationships. They are active agents in these roles, both giving and receiving support and care in multiple ways. The reciprocal nature of care, especially in family life, was important to several young people in this study, who strongly identified with their emerging role as a provider of care within the family unit as an adult as well as receiving support and care from parents. 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.

Relationships are critical for establishing and sustaining young people's sense of belonging and connection. When relationships support young people to thrive, they have shared qualities. They are mutual and reciprocal, and both partners see positive qualities and contributions in each other. They are underpinned by respect, and this is embodied and demonstrated in actions and interactions. They are evolving and responsive to change, and reinforce capability and protect against isolation and loneliness. They develop and strengthen over time. Being lonely impairs belonging, and action is needed to redress loneliness for young people who feel lacking in friendship.

Being known and valued is a core requirement for young people to have a secure sense of belonging and personal identity. When young people have positive and supportive relationships (as described above), 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.

It is important to distinguish being known and valued from being known and talked about or treated in ways that make young people feel uncomfortable – these are the positive and negatives of close knit ties. 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).

9.2 Implications for service systems, structures and 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 does not rely on people understanding and advocating for their own entitlements to high quality, relational support. Instead, it creatively works in partnership with young people and their families to develop a framework to scaffold their participation and personal development, person by person. It is not instrumental and it is not tick-a-box, but responds to the needs, rights and aspirations of young people as individual and unique.

Young people place strong importance on relationships, friendship, alliance with others and not wanting to stand out. A balance between individual support and opportunities for developing and sustaining relationships in collaborative spaces is important. Group-based programs may inadequately address young people's expressed needs or wants to be known and valued, to have mutual and respectful relationships and to avoid being viewed predominantly in terms of their impairment. 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.

Support needs to focus on the person and also build collective capacity in their regional location. 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 planning. Some of the barriers in young people's lives can be minimised or overcome with the creative use of funding – lack of control over who provides personal care, transport which doesn't operate between villages and towns in the school holidays, access to friends who live a distance away. Other barriers are more resistant, such as finding work or moving out of home. 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. 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 'twin track' approach to individual and collective capacity building is necessary.

Education and training tailored for young people and for those who support them is needed. By focusing on what it is like to receive and give effective personalised support, this will help inspire creativity in workers, support a growing level of aspirations in young people, and raise both young people's knowledge about the skills needed to make and sustain relationships in the forthcoming policy and practice changes. 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 young people and for those who support them in various settings, such as teachers, health professionals, disability services workers, sports and leisure settings. It is not sufficient to support relationship development as a concept – a skill set is needed to have the capabilities to make friendships and wider social relationships and to facilitate them.

Youth-oriented support makes a difference to young people's personal identity. Spending considerable periods in disability services brings young people into close contact with support workers and managers who are in the main quite a lot older. The suite of options from which young people are able to choose activities and programs is often determined by service providers and support workers, and their ideas and preferences may in some cases be at a remove from young people's ideas of fun. While many activities and initiatives undertaken by young people in this project were exciting and creative, some of the activities featured in the photos and observed in the visits were not very youth-focused, and at times seemed to have little resonance with some of the young people. 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. 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. These electronic media have been little used to date by people with cognitive disability, and accessible information, communication and promotion avenues are ripe for exploration.

Violence and interpersonal harm stops young people from feeling a sense of belonging and connection. Some young people in this research had experience of these harms. Interpersonal harm in particular tends to go 'under the radar' of policy frameworks, which focus on responding to incidents of abuse and neglect. The nature of many of the harms experienced by young people in this research are different – they 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 impairs young people's sense of belonging and connection, and has a significant effect on their developing sense of identity, optimism, confidence and wellbeing. 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. Evidence-informed, peer-based approaches will likely have most benefit in attending to the belonging and connection needs of young people in this position.

9.3 Implications for communities

Place is a foundational site for relationships. If a sense of place is insecure or experience of place is unsafe or unwelcoming, this is destabilising for young people's sense of belonging.

Some people talked about feeling a lack of confidence to participate where they did not feel welcomed. 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. Others talked about avoiding places in their community due to fear of what might happen there. Young people who were more reliant on support had less opportunity to put self-protection strategies into place to keep themselves safe, and were reliant on others to stay safe. There are tensions in resolving this fear of harm when it may be legitimate, and where the alternative segregated places carry a different set of risks.

The quality of relationships is the major determinant of how young people feel about their regional communities. The impact of living in a regional community on young people's participation is felt by them in both positive and negative ways. 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).

Regional lifestyles open up some opportunities, but can make it harder to achieve transitional milestones as a becoming adult. Living in regional areas affects the types and ranges of settings and activities available to young people – for example, there are fewer shops and formal leisure activities, but more interaction with the natural environment and opportunity for owning large animals. 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. Being known has positive and negative implications.

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.

9.4 Implications for research

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 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, building on the clear interest and engagement of the young people in this research with internet-based technologies.

The high rates at which young people disclosed negative experiences and the impacts on their 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.

There is considerable merit in considering how the findings from this study can extend or modify existing theorising of belonging, connection, social inclusion and disability. The results (with their central focus on the importance of relationships and the myriad ways these intersect with space and place), 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.



▶
Me and Jess running amuck lol.
By Megan

10.

Next Steps

A number of directions for further action emerge in response to the results of this research. These centre on localising action; providing education and support to young people and their supporters; addressing barriers to belonging; building a strategic research base; and collective knowledge sharing.

Engaging with young people and those who support them about priority areas for building belonging and connection in regional communities.

As a first activity, the key results of the research, and the implications arising from them need to be discussed with the communities in which the research took place. Seminars in each community will provide opportunities to speak with young people, families, workers and managers of community services about the priority areas for action in policy and practice to better support belonging and connection.

The priorities identified by regional community members will be promoted through a short report which will accompany this project report, but they will also motivate change at local levels.

Providing education, training and support about developing and sustaining relationships to young people and those who support them.

Education and training for young people and those who support them about relationship building is an important step in crafting responses which go beyond young people's participation in activities to their embedded inclusion in communities. For this to work, young people and their families need education and support in friendship and relationship building. People working with young people need professional development in the skills required to assist them to develop and sustain relationships, in understanding the importance of relationships, differentiating between friendship and wider relationships, and being guided by the young people's relationship aspirations and preferences. Community groups need practical support about how to meaningfully include young people, so they can feel more confident in becoming welcoming spaces which relationships can develop.

Recognising and acknowledging the high rates of negative experiences in young people's lives.

As well as activities to build positive relationships and a sense of belonging and connection, acknowledgement is needed of the high levels of negative experiences reported in this study, and confirmed in the limited amount of previous research. Social isolation and loneliness, lack of adequate safety, and unacknowledged loss and grief all appeared at levels higher than for young people without disability. These require a range of different responses, but they require action as a matter of priority to prevent long-term damage to young people. There are important gaps between young people's lived experience and current policy in key areas, including support planning, education and abuse prevention and response.

Further research which addresses the known evidence gaps in disability research.

The recent audit of disability research identified priority areas for research which are currently significantly under-represented in the disability research base (Kavanagh et al., 2014). These include:

- inclusion and participation of children and young people with disability in everyday life
- co-production of research with people with disability
- experiences of people with disability as users of specialist and mainstream services
- research specific to people with disability living in regional and rural areas
- research around safety and harm

In each of these areas, this study identified new knowledge which needs further investigation, and which provides important opportunities to build on known evidence gaps in these strategic priority areas.

Building collective knowledge on best practice in inclusive research with young people with disability.

This research provides a detailed example of inclusive research. The work of other researchers working with children and young people with disability could be brought together via a symposium and subsequent development of guidelines about disability inclusive rights based research, in keeping with the recommendations of the audit of disability research that 'there is an urgent need to stimulate research which is co-produced with people with disability and their representative organisations and to develop guidelines for the ethical conduct of such research (2014, p.8).

I am fascinated by the history of things. By Possum ▼



11.

Conclusion

This study confirms and extends existing research about belonging and connection of young people with cognitive disability in regional communities, providing rich and important insights and practical ideas for change. The critical importance of relationships in young people's lives is manifestly apparent. The impact, both positive and negative, of friendship in young people's lives is strongly conveyed through the participatory approach and photographs, which show relationships and their absence very evocatively. The relevance of place, particularly regional place, in young people's lives is made clear in this study in ways not previously documented. Most important for us, though, has been the opportunity to work alongside the young people as collaborators in this project to help inform future policy and improve support programs and services.

Partnering with young people with sometimes significant support needs in collaborative research processes involving the collection and analysis of their own research data, and witnessing the exhibition of their work as artists has resulted in rich, rigorous research. This project exemplifies how young people with cognitive disability can be recognised in and through research as human persons worthy of dignity and respect who are capable of sharing their views, experiences, goals and dreams for the future. This is a delicate enterprise, individual and diverse. Any small success in this project is reflective of the wider value that young people told and showed us that they hold in their lives for supporters who can be with them, come to know them, acknowledge their experience, celebrate their contributions and, importantly, help to reveal understandings that might open the way for others' lives to be enhanced. For us, the project has been a great privilege and a defining learning experience.

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13.

Appendices

Appendix 1: Research design

Three phased sets of research activities occurred over the life of the research:

PHASE ONE: establishing young people's understanding of belonging and connection

Activities in the first phase of the research centred on the first of two narrative interviews with young people and the establishment of the photographic projects.

Structure of the projects

Each of the three research groups worked a little differently from the outset. In site one, in keeping with the nature of the program as a respite service, the young people came together for a weekend camp which included a series of activities as well as the research interviews and workshops. In site two, the interviews ran across three consecutive days and a planned workshop on the fourth day was changed to a practice photography session when the venue, membership and needs, of the group changed at short notice. In site three, interviews ran over a two week period, and three workshops were held to accommodate the diverse schedules of participants.

Information and consent materials were posted to young people and their families prior to the first meeting with the researcher. Two versions of the information for young people were developed, in easy read English and a pictorial booklet with minimal language. For people under eighteen and those who needed support with consent, parental or family consent was obtained.

The information and consent materials had been posted to all prospective participants, and in many cases young people recognised them when shown them again in our first meeting. In one site, young people had been enthusiastic about the consent materials, reading them to each other and taking them home to show family members. Their support worker said the tone and style of the document matched well to their reading level and piqued their interest. However, another boy mentioned at the end of his mapping interview that he nearly didn't come, because the materials had a picture of 'those people' [people with visible disability] on the front cover. After this, a second set of materials were developed for people with lower support needs with fewer pictures and a more 'serious' look and tone, and people sent the resource likely to be most appropriate.

Consent or assent of all young people was discussed and obtained before or at the mapping interviews.

Workshops with support staff

Prior to interviews and workshops with young people in all regions, a workshop with staff and the project coordinator was held to brief key workers on the project, the research, and the roles of supporters. A resource folder was developed for staff with guides on providing support, ethics, and technical assistance with photography. Appendix 2 provides further detail.

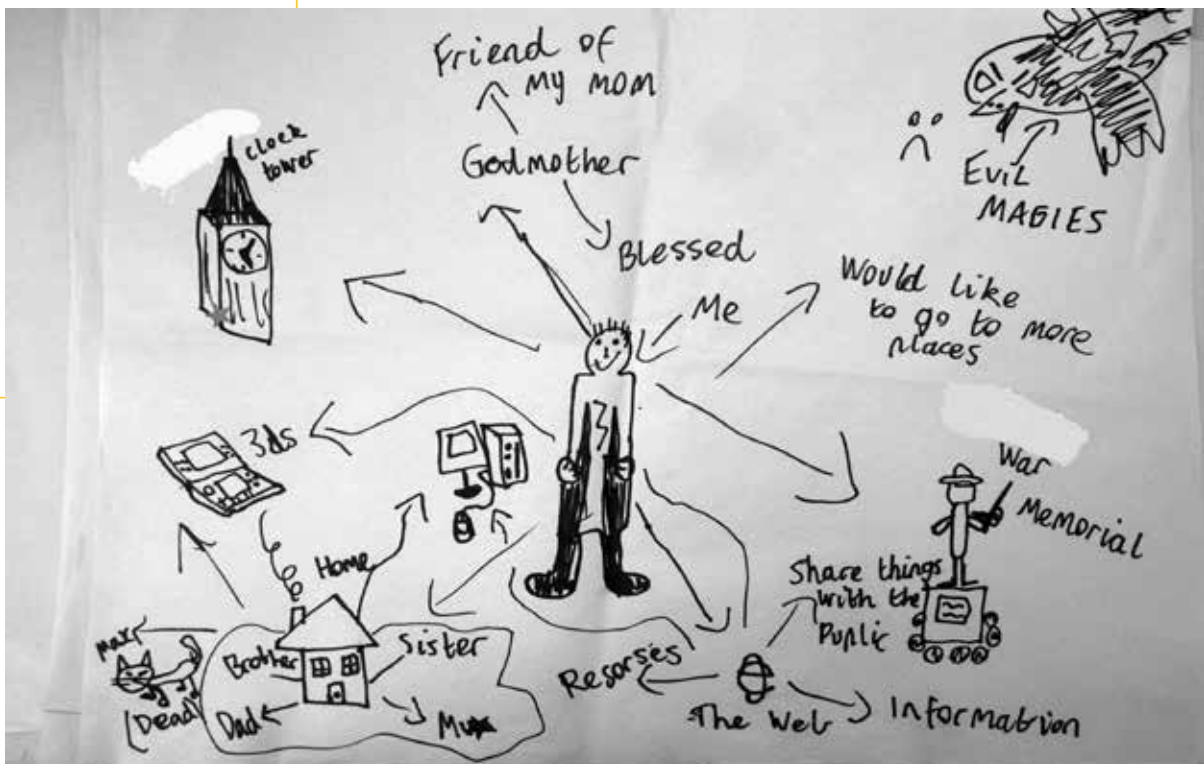
Mapping interviews with young people

The purpose of the first interview with young people was to map their community and relational connections, and to talk about the meaning of these to them. Additionally, we hoped to find out their perspectives on what it means to belong and be connected, and what they expected it would be like to be part of a research project. This was a big agenda to cover in a single interview, but due to distance, we did not have the opportunity to divide the content across two interviews and wanted to gather this information before the photography projects started.

Interviews were held in private or quiet spaces within the service environments, and young people were invited to have a support person present if they wanted additional support, either for part or all of the interview. Thirteen of thirty had a supporter present, in all cases a staff member. Interviews were informal and conversational. A range of stimulus materials were provided – such as magnet connector rods, Rubik's cubes, soft tactile balls and drawing materials – and used casually by both young people and researchers as they chatted. This proved an effective strategy for diffusing any nerves or tension, especially at the beginning of the interview.

In all cases, interviews with young people followed the same format. Young people who were able to respond to the question were asked about their expectation of the project at the start of the interview. The main body of the interview then consisted of young people and a researcher together drawing a map using images or words to show the places and people important to the person, while talking about why these connections had meaning to them.

These maps were developed in several ways. Fourteen young people either wrote or drew their own picture maps. Nine maps were drawn by the researcher under the direction of young people, and five maps were completed by both young person and researcher. Two maps were drawn by young people with a support worker outside of an interview, as they were away during the interview week. Two people with limited verbal communication used pictograms for their maps, and supporters assisted in narrowing the choices to things they knew young people related to, with non-preferred activities included to check for discrimination.



▲ Angus' map

At the conclusion of the map making, young people were asked about what they thought it meant to belong, and what it meant to be connected to other people. As a final activity, the researcher connected the map to the photographic project, pointing out the number and range of sites the young person had identified as possible places to start taking photos about what helps them to feel like they matter.

With the consent of participants, interviews were digitally recorded and later transcribed. Visual material (e.g., maps) was photographed, and young people offered the option of keeping their map. All resulting data was coded and thematically analysed with the assistance of NVIVO software.

Belonging and photo workshops with young people

Following interviews, workshops were held with young people to establish the photographic projects. Again, these were different in each site, due to the differing requirements of each group.

In site one, the workshop was divided into two, the first part held in the evening of the first day and the second part in the afternoon of the second day. The first workshop did not go to plan, as the young people were tired, unfocused, and ready for their usual after-dinner activities, which were much more active. The workshop was adjusted 'on the fly', and a much condensed, practical skills-based session given instead, with information needed to support the following day's photo activity and the research intention of the project provided in place of the belonging activity scheduled. The following day, the second workshop was adjusted in response to the group's preference for experiential learning, and the photos they had taken during the day (following a belonging photo activity sheet) were made into a powerpoint presentation to demonstrate the research aim by sharing their implicit knowledge about the subject and the expertise of their peers.

In site two, the needs of the group were such that a very practical approach was needed to ensure that the young people were left with a hands-on understanding of what kind of photography the project was asking for and what it means to be a researcher. They worked across a day with support workers to take photos of places and activities that they particularly enjoyed, and with the researcher, individually uploaded the photos onto Flickr and captioned them. This process also helped the support workers to see how the project would work in practice.

In site three, three workshops with young people were held. The same process was used in each group. This was the only site which used the workshop framework as developed. It included small group activities and games which worked through the aims of the project; research roles and expectations of young people, facilitators and research team; ethics; privacy and confidentiality; developing/refining the research question young people wish to address; and clarifying the public output young people would like to see from the project. The individual contributions of each participant about belonging and connection were brought forward (with their consent) into the workshops for group discussion, confirmation and addition.

PHASE TWO: photographic research projects in three regional areas

In keeping with principles of inclusive research (Seale & Nind 2010), the project also built young people's capacity by using a participatory research process based on photovoice, which is an accessible, visually rich research method (Jurkowski 2008; Wang et al.). This allows for the involvement of young people as co-researchers in research design, collection of data (through photography), analysis of photographic data, and dissemination of results through a public photographic exhibition of key images.

Supporting young people's progress

Our initial research design had involved a structured process for supporting young people to discuss and learn together about the substantive issues of connectedness and belonging,

about research skills for photovoice, including use of cameras, and about how to select a project topic. After the initial round of workshops, it became evident that we would need a more individualised approach to the project to respond effectively to the very diverse group of young people who had been recruited to the project and their expressed wish and need for multiple support strategies.

It was clear after meeting all of the young people that they were either receiving quite a lot of support to participate, or participating quite independently. To maximise support at both ends of this continuum, we developed a series of activity guides in easy English (Appendix 2). Our thinking here was that these would provide content and process support to young people who were working quite independently as they progressed with their research (particularly the group in site one, who were not in frequent contact with the project facilitator), and also help supporters avoid asking leading questions or unduly influencing the choices of photos taken for other young people receiving assistance with their photography. These activity guides were provided to each of the site facilitators, with guidance for providing them to young people as time progressed, and/or as they indicated they were finding it hard to think about what to photograph to show belonging and connection, or what mattered in their lives.

The resource sheets covered

- My town
- Portraits/people
- A day in my life
- Getting from A to B
- My future
- How do people see me?

In sites two and three, some of the young people had time to take photos structured into their weekly routine, and their regular support workers assisted them in thinking about what they wanted to document, and photographing these things. In site one, the young people worked more independently, and were provided with cameras to take home between workshops. This had mixed success, and additional work was done in workshops to support young people to document some of the things that were important to them which were accessible on the day. Across all three sites, people drew on photos from home and other community sites and many brought photos from their Facebook pages into the project.

Young people in each site were supported to upload their photos onto a private account in Flickr, an online photo management and sharing application. This enabled them to caption each photo, store them in a virtual album, and share the developing work with the researcher as the project progressed. Flickr account details were held by the facilitator in order to maintain the privacy of other co-researchers sharing the account.

At the time of uploading, the process encouraged each person to think about whether each image was private (just for their own use), just for the research, or for possible exhibition. Private photos were not uploaded, but the young person thanked for sharing the image and talking about it. The uploading process could be redesigned to allow more independent uploading by young people using phones for photography by opening separate accounts for individual young people.

In order to track process learning, facilitators were asked to maintain research diaries or notes throughout the photo data collection phase. This had limited success, due to the busyness of facilitators. Researchers maintained frequent contact with facilitators in all three sites, checking progress and trouble-shooting as the young people took more photos.

Analysis interviews

At the three-quarter point in the projects, a second interview was undertaken with each young person to explore with them their perspectives on belonging and connection, using their photography and captions as the stimulus. Young people were also asked about their experience of co-research (the experience and the process), and their recollections of the project purpose. After discussing them, each person chose key photos as the basis of their contribution to the exhibition.

Printed out copies of all photos taken by each young person, with their captions printed underneath, were used to stimulate discussion with them. Each person went through their photos one by one, talking about why they had taken them and what was important about the photo or its context. The stimulus question 'tell me about this one' in most cases was sufficient to generate discussion about the photo and its meaning. As young people worked through their individual images, the researcher clustered them according to subject.

Once all images were on the table, each person selected up to eight images which 'told a story' about what was important to them, what helped to feel like they mattered, or what helped them to feel like they belong (according to which concept resonated). Once the images were selected, young people chose the two most important images to be blown up as large single images, and pasted the other six into a collage. A 'I' statement was developed by each person as part of their collage in response to open-ended questions about thematic areas appearing their images and discussion. Many of these statements centred on being capable in various ways, being a good friend, and having positive emotional qualities.

People with high support needs demonstrated clear choices of images and captions which reflected their preferences in daily life (according to their supporters). In their interviews, supporters assisted by selecting sets of three photos for them to choose between, with known non-preferred options included.

At the conclusion of the photo research, individual interviews were conducted with key support workers and the project facilitators in each site. The focus of the interviews was on gathering support workers perspectives on how the young people were supported to participate in the project, and the facilitators and constraints on their participation in the research.

On-line survey of young people with cognitive disability in additional regional communities.

In addition to the photographic project, an interactive on-line survey of young people with cognitive disability was developed and run. The survey built on the findings from Phases 1 and 2 and was designed to seek additional information particularly on how young people identify themselves; the relationships they identify as most important; preferred and non-preferred aspects of regional living; and connections between place and satisfaction. The survey was distributed and promoted widely through organisations providing information, support, advocacy and service provision to young people with cognitive disability. Twenty six additional young people contributed to the research through the survey.

PHASE THREE: sharing results in the public domain.

In all three sites, public exhibitions were held to profile the work of the young people as researchers and artists.

In site one, the exhibition was held in the regional town public gallery over a weekend. In site two, the exhibition was held in the regional town art gallery over a two week period. On request from the gallery it was extended for a further week. In site three the exhibition was held in the building of disability support service, centrally located in the regional town, over a three week period.

All three sites held popular launch events with large attendance (80 – 120 people), music performances by young people, speeches by local dignitaries, and public media in local radio, TV and print. The artistic and research contribution of each young person was recognised in a speech by the researcher at each event.

Belonging project website

As the project progressed, the idea of creating a website was suggested by some of the young people, who were eager to both share their photos and see the work of people involved in other sites (www.belonging.new.au). The exhibition and website provided an opportunity for group members to demonstrate new skills and to share learning with other people involved in the research, as well as interested community members and a much wider audience.

Seminars for sharing research results

Seminars will be held as the culminating activity in each of the participating regional communities and include young people with cognitive disability, academic researchers, policy makers, family members and other supporters, community members and disability service providers. These seminars will provide an important opportunity for discussion of the key research findings and recommendations. This report and its plain English accompaniment will form the foundation of the seminars.

Appendix 2: activity guides

Activity guides on six topics were prepared and distributed to young people (see method, above). No order of use was prescribed or suggested. The two below are a sample. 'People' is included in both easy and easier read formats, as all were produced in two versions to accommodate the needs and preferences of the group.

The resources covered

- A general 'taking photos' introductory activity
- People
- A day in my life
- My town
- Getting from A to B
- How do people see me?
- My future

Appendix 2 resources



People

We would love to see:

Pictures of you
What do you want other people to know about you?


Pictures of other people
How can you help someone else tell their story in a photo?

Pictures together
What story can you tell together in a photo?

This time, we want to see YOU in your photos!

- What story can you tell about you?
- Is there something you could hold in your photo that will help you show what's important to you?
- Is there a special place where you can take your photo?

- You can ask someone else to hold the camera, or you can take a selfie.
- If you don't want to have your face in your photos...would you like to just have your hands or feet?



People

Can you take some photos of:


YOU!

PEOPLE YOU LIKE

Can you be in a photo with someone you like a lot?

Who might be in your photo?

- You!
- A person you love
- Your family
- A friend
- A person who helps you





My town

- *What is it like to live in your town?*
- *Where is your favourite part of town?*
- *What is good about living here?*
- *What is not good about living here?*

We would love to see:

Pictures of your town

What do you want other people to know about your town?

Pictures of people who live here

Who matters to you in your town?





in
the picture

AUGUST 2014 - FINAL REPORT

Sally Robinson

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