

# The Belonging Project



## THE BELONGING PROJECT REPORT OF OUTCOMES

### Authors

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## Acknowledgements

The Belonging Project acknowledges the Traditional Owners of the Tweed, the Bundjalung People, and pays respect to elders, past and present and future.

We would also like to extend thanks and acknowledge the children and families who participated in this research who so openly and honestly shared their stories with us.

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# 01 Executive Summary

The Belonging Project is a participatory research project, talking to children up to the age of eight with additional needs and their families about what it means to feel included and connected in the Tweed Shire Community. Funded by Family and Community Services NSW (FACS) within the skills development stream of Stronger Together 2, the broader aim of the Belonging Project is to work with stakeholders across the community to develop a framework for building inclusion in community settings. This report details the results of the research which will underpin the framework. Through taking a research approach, we aimed to ensure that the experiences and voices of children and families form the basis of plans for action in the Belonging Project.

Little is known about the ways that children with disability and their families connect with places and people, or about their perspectives on belonging, particularly within regional communities. Connectedness and a sense of belonging are not only critically important for wellbeing but also for understanding inclusion and exclusion. In order to support responsive social policy aimed at providing well-targeted, individualised support for children with disability and their families, there is a need to improve understandings of the ways in which they develop meaningful and fulfilling relational connections within and beyond families, schools, programs and services, and with places and people in their local community.

The Project Team from the Northern Rivers Social Development Council and the Centre for Children and Young People at Southern Cross University engaged with 33 families across the Tweed Shire. Children were asked to draw a map of their lives to show the places they like to go and the people they go there with. Parents were then interviewed about what worked well and what the barriers were to inclusion for children and families. Half of the families were Aboriginal and this was only made possible through a partnership with an established Aboriginal service provider. Many of the families approached did not have the time or capacity to take part in individual interviews, therefore a group method was developed to bring families together. These events were based on delivering fun social activities for kids, supporting parents to take part in the mapping and discussion process. The project design has been adapted to continually build inclusion and reflect the research findings as they emerged.

The outcomes of the research are built on the lived experience of children and families and tell us what is important and what makes it hard to feel like a valued member of the community. For Aboriginal families, racism presented a layer of compound disadvantage. For non-Aboriginal families, similar feelings of judgement, distrust, and ill-treatment were experienced on a basis of children not fitting the 'norm'. Children, due to their age, focussed primarily on the things they enjoy in the community - the park, beach, rivers - activities with their families. Demonstrating an immense resilience, all families had a vision of a better life for their children and shared many innovative strategies for overcoming obstacles and fostering inclusion.

The recommendations or 'Building Blocks' from the report capture a foundation for working inclusively and in a way that works for kids. These include consulting in ways that recognise the expertise and experience of parents, gained through raising their children; providing options and choice; recognising there is no norm when it comes to kids with additional needs; being mindful that parents facilitate belonging for kids and that the family unit must be considered as a whole; activities should be sustainable and not a further strain on families' resources; relationships are key to belonging and kids and parents still want to have fun. Finally the community needs to prioritise Closing the Gap of disadvantage for Aboriginal children. There is something everyone can do to make lives easier for children and families and share the responsibility for building an inclusive community.

## 02 Background

In June 2012 FACS Ageing, Disability and Home Care (ADHC) funded the Northern Rivers Social Development Council (NRSDC) within the skills development stream of Stronger Together 2, which aims “to reconfigure the service system in a way that was more sustainable and would get the best social and economic outcomes for people with a disability, their families and carers, and for the broader community.”

Representatives of the project working group attended a community consultation meeting at Tweed Valley Early Childhood Intervention Service which commenced ‘a conversation on how to make a good life for children’. The feedback from this meeting and an initial scan of the literature were combined and the working group developed a focus on a participatory research and capacity building project titled ‘The Belonging Project’.

A Research and Capacity Building Project Officer was recruited by NRSDC to coordinate and carry out the activities of the Belonging Project, working in partnership with the Centre for Children and Young People (CCYP) at Southern Cross University.

The project purpose is to increase inclusion for children with disability up to 8 in their communities in the NSW Tweed Valley region (including Tweed Heads, Tweed Coast, Murwillumbah and outlying villages) by using capacity development approaches to respond to the assets and strengths identified by children and families. The project will:

- use participatory research methods to explore the facilitators of community connectedness and belonging with children up to 8 and their families
- use the results of this research in combination with asset- and strengths-based approaches to develop a framework for building capacity and inclusion in local communities, and
- map and support collaborative engagement with key individuals, groups and organisations underpinning the project, including emerging capacity development and education strategies which promote inclusion of children with disability.

The aim of the Belonging Project is to work with stakeholders across the community to develop a framework for building inclusion in community settings. The project aims to grow the skills and knowledge to become a community in which everyone has a say, has a range of relationships and can go to the places they want - when and how they choose. It is a strengths-based project, so the focus is on the existing resilience in the community and learning from the good work that is already happening. All people who have a stake in the outcomes - children, families, services, organisations and businesses - will have a chance to give feedback and advice on the interview process, research findings and take part in capacity building, planning and activities.

The Belonging Project takes a participatory research approach. Key individuals and groups, including children, have been involved in the design, implementation and oversight of the project. A reference group has met regularly throughout the first phase of the project, with members representing parents, early childhood educators, service providers, local and state government, and an Aboriginal advocacy organisation. The reference group has provided guidance and advice on the design of the project, interview questions, emerging themes from data and capacity building strategies.

The project is being conducted in three phases:

- Phase one has focussed on participatory research with children and families and the development of collaborative approaches with key stakeholders.
- Phase two has involved the analysis of data, and using the emerging research outcomes to work collaboratively with key individuals and groups to further develop capacity building networks and strategies.
- Phase three will include the collective development of a framework for community capacity building and focused capacity development activities with individuals and groups.

Currently the project is partway through phase two, and the results and building blocks from this report will inform the development of a framework for capacity building. This will involve consultation through two forums, to ensure the research outcomes build from lived experience to increase inclusion and a sense of belonging for kids and families in the Tweed Community. Families, service providers to kids with disability and the broader community, and key community linkers will be critical participants in these forums.



# 03 Literature Review

## Introduction

In an Australian population of a little over 22 million people, about 4 million, or 20%, report as having a disability resulting from a health condition. Nearly 1.3 million people have a “profound or severe disability”. An estimated 7% of Australian children had a disability in 2009 and, of these, over half had profound or severe core activity limitations (4%). (AIHW 2013)

## Research on belonging and connectedness

While closely related, connectedness and belonging are different. Connectedness relates to the linkages between a person and other places or people, while belonging refers more to the emotional attachment that people feel about these connections. Both impairment and disabling social attitudes impact on connectedness, for instance in shaping who children and families meet, in what contexts and how relationships develop.

Connectedness and a sense of belonging are not only critically important for wellbeing but also for understanding inclusion and exclusion. However, little is known by researchers or policy makers about the ways that children with disability and their families connect with places and people, or about their perspectives on belonging, particularly within regional communities. Developing a clearer picture of this experience may provide new opportunities to build on the existing knowledge and capacity of community members.

Several studies present the perspectives of young people with disability, in which they talk about friendship as a key concern – making, keeping and managing friendships (Avramidis 2010; Frostad and Pijl 2013; Kuo et al, 2011). Having friends was viewed by children in several studies as a source of resilience and support against poor treatment by others. Making and keeping friends was also a source of tension for some young people (Salmon 2012). Recent research by Vandekamp (2013) found school students with disability who felt a strong sense of belonging in their nuclear family were protected from struggling with high levels of loneliness. The limited amount of existing research also shows that for young people with cognitive disability, having few social connections is not the same as feeling isolated (Foley et al. 2012).

From a family perspective, previous research has found that families with strong informal support networks are more resilient and better manage the needs of their children with disabilities; that families trust friends and peers as sources of information and referral; and that how families are treated at diagnosis can have a long term, lasting effect on the sense of control, confidence and the expectations of families (Moore et al. 2011).

When kids and families don't feel connected or like they belong, there is a range of different ways that this affects their lives. The places, relationships, and cultures that are important to people can be spoiled or damaged. (Graham & Fitzgerald 2010). Belonging and connection is closely linked to happiness, positive mental health and social capital (Hill 2006), although, connections may also be negative as well as positive (e.g. pressures to conform, intrusiveness of services into family life).

It is also very important to see belonging and connection as part of a broader picture about inclusion. Research with adults with cognitive disability about their experience of inclusion and exclusion 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 so important for other community members (Milner & Kelly 2009; Salmon 2012). Responsibility for inclusion is also set largely at the feet of people with disability and their families (to behave in a ‘normal’ fashion, to gain employment, to engage in mainstream community activities). The role of institutional structures, discrimination and deeply ambivalent social attitudes towards people with disability are frequently overlooked (Hall 2010, 2004).

Some early research on inclusion focused on the physical presence of children with disability in community settings. More recent research emphasises the connection between places and relationships. Some examples of this include highlighting the importance of social space where young people feel trusted and able to have fun and have private conversations with friends (Hoskin 2010); recognising the cultures of groups and having strategies to change these (e.g. addressing bullying), rather than focusing on changing children with disability (Davis & Watson 2010); and having accessibility adjustments made which fit the space-time rhythms of school life, leaving kids with disability feeling no different to other kids (De Vet et al, 2012).

## **Setting the scene**

Policy relating to children with disability and their families at all levels of government are characterised by a shift from welfare models to person-centred practices and resourcing the sector to adequately deliver these changes. At both state and federal levels there has been a significant investment in funding and planning for moving toward a more equitable future. There has been an overwhelming recognition of the need to consolidate for moving forward to a best practice education and care system for young people that ensures children are ready to enter society and fully participate in a meaningful way. Throughout this process the emphasis on consulting with and designing programs with the input of children, families and people with disability has been apparent. Below is a brief overview of the policy frameworks guiding the work of government and the community, education and care sectors at local, state, federal and international levels.

### **NSW Local Government Access and Inclusion Action Plan**

Tweed Shire Council, in line with state planning requirements, is developing a policy and action plan on access and inclusion. These documents will guide priorities in planning and development over the life of the Access and Inclusion Action Plan. Consultation has occurred and an action plan will be put to Council with a raft of measures within Council’s remit including infrastructure, planning, amenities and partnerships (Tweed Council, 2012).

### **NSW Government 10 Year Plan - Stronger Together**

Stronger Together has been rolled out since 2006. Now in its second phase, it is delivering increased funding for supports available to children with disability and their families. The focus of these supports in relation to children has been on increasing places available in early intervention and prevention services. A key shift of the second phase of Stronger Together involves a move towards individualised funding arrangements. ADHC (2012) report this shift to be in response to feedback received from people with disability for greater choice and flexibility in seeking supports from services and in the community.

The principles of such an approach are that:

- people with a disability, their families and carers are the primary determiners
- people with a disability are supported in their planning and decision-making
- people with a disability are offered choice, portability and flexibility in funding and supports
- the allocation of resources to a person is based on assessed needs (AHDC, 2011).

### **National Disability Strategy and the NDIS (Disability Care Australia)**

In Australia the situation has for some time been that the level of care and support received as a person with a disability differed dependent upon where you live, the laws governing that state and the disability specific services located near you (NDIS, 2012). The National Disability Strategy 2010-20 was devised in part to make this process fairer, bringing in a unified national approach to care and support for people with disability and their families (FAHCSIA, 2011). A 10 year National Policy Framework sets out priority areas for action and is underpinned by the following three key platforms (PWC Report):

- The human rights imperative – people with a disability must be afforded the same rights as all other Australians
- The social imperative – inclusion and participation in everyday life for people living with a disability is paramount. Everyone is part of the solution and this involves changing attitudes
- The economic imperative – people with a disability need to be supported and encouraged to contribute through workforce participation and other productive avenues.

Following the release of the NDS the Productivity Commission conducted an investigation into current care arrangements and produced the Report into Disability Care and Support. This further recognised the right of people with disability to individualised funding and to have a choice of services and access to mainstream supports. The outcome of this report was a recommendation for the Government to fund a National Disability Insurance Scheme. The NDIS bill passed through Parliament on the 21st March, 2013 with a roll out to four launch sites beginning in July 2013 and the full scheme commencing in July 2017(FAHCSIA, 2013). A name change to Disability Care Australia was announced to be the program name and public face of the NDIS.

### **Council of Australian Government's Reform Agenda for Childhood Education and Care**

The National Early Childhood Development Strategy, 'Investing in the Early Years', was agreed by the Council of Australian Governments (COAG) in 2009. It set out four streams under which reform would take place: Providing Access for All Children to Preschool; Closing the Gap on Indigenous Early Childhood Development; Better Child Care and Early Childhood Education; and Keeping Australian Children Safe from Harm.

### **National Quality Framework**

The Australian Government's National Quality Framework for Early Childhood Education and Care came into effect in January 2012. It encompasses a range of legislative improvements to the quality and provision of care including qualification, educator-to-child ratios and other key staffing arrangements (DEWR, 2012). One central accreditation organisation has been established to streamline administration for services, with the aim of allowing more focus on the delivery of education and care (COAG, 2009). Under the National Quality Framework sits the Early Years Learning Framework for children in care between the ages of birth and 5 years, and the My Time, Our Place—Framework for School Age Care in Australia.

### **Early Years Learning Framework**

The Early Years Learning Framework (EYLF) is part of the COAG reform agenda for early childhood education and care and is a key component of the Australian Government's National Quality Framework for early childhood education and care (DEWR, 2013). The EYLF framework 'Being, Belonging and Becoming' has 5 key outcomes to ensure children- have a strong sense of identity; are connected with and contribute to their world; have a strong sense of wellbeing; are confident and involved learners; and are effective communicators. It provides Early Child Care

workers with a framework for the practical delivery of services. Both the EYLF and the My Time, Our Place Frameworks serve as a reference for Early Childhood Practitioners to implement the values laid out in the United Nations Convention on the Rights of the Child (the Convention).

### **United Nations Convention on the Rights of the Child (the Convention).**

The Convention states that all children have the right to an education that lays a foundation for the rest of their lives, maximises their ability, and respects their family, cultural and other identities and languages. The Convention also recognises children's right to play and be active participants in all matters affecting their lives (DEWR, 2009). Although with the objectives and principles of the Disability Services Act 1993 consistent with the Convention, Australia ratified the Convention on the Rights of the Child in December 2009, ensuring a duty of the Government that all children in Australia enjoy the rights set out in the treaty including the following core principles:

- the right of all children to survival and development;
- respect for the best interests of the child as a primary consideration in all decisions relating to children;
- the right of all children to express their views freely on all matters affecting them; and
- the right of all children to enjoy all the rights of the CRC without discrimination of any kind.

## **Review of strengths based approaches**

Existing research demonstrates that families with strong informal support networks are more resilient and better manage the needs of their children with disabilities, that families trust friends and peers as sources of information and referral, and that how families are treated at diagnosis can have a long term impact, lasting effect on the sense of control, confidence and the expectations of families (Moore et al, 2011).

Building on the strengths of families will support a community capacity development focus in the project, and the development of a Framework for Capacity Building in consultation with families. This framework model will draw on existing conceptual approaches to community-building, that ensure the research data is incorporated into a strengths-based framework to build capacity at a community level.

The approaches include Asset Based Community Development (Boyd et al. 2008), Wraparound Planning and Positive Youth Development Models for asset building communities (McCammon, 2012).

### **Wraparound Planning**

"Strengths-based" is a key component of the Wraparound Planning Process, used in individualised service planning and is defined as "the assets, skills, capacities, actions, talents, potentials, and gifts" of children and families (McCammon, 2012). Other key features of Wraparound Planning which could be applied to this Project include:

- Service planning which builds on the strengths of young people and recognises that fostering children's skills contributes to the formation of a positive self identity.
- Providing a variety of options is a powerful part of a solutions-focussed approach, as it is more likely families will relate to an expanded range of opportunities.
- Consideration must be given to balancing the focus on strengths while acknowledging the many difficulties families face. (McCammon, 2012).

### **Positive Youth Development (PYD)**

While Wrap Around Planning works with children in a family and service orientated setting, PYD operates more broadly, situating children within their communities (McCammon, 2012). It focuses on utilising strengths as a resource and engaging youth within schools, organisations and peer groups. Some features of PYD which are relevant to this project include:

- Characteristics of effective Asset Building Community Programs commonly utilise multiple community settings and combine activities in an intentional way to promote the development aim.
- School based programs to promote Social and Emotional Learning (SEL) have utilised PYD. They involve developing strengths in and out of the school setting, with parents and the community partnering to deliver activities with the aim of preventing problem behaviour.
- Beyond the immediate family, engagement of school and other community partners will contribute to developmental well-being (McCammon, 2012).

### **Asset Based Community Development (ABCD)**

ABCD is grounded in implementing strengths-based as opposed to deficiency-based approaches to development. It acknowledges there is a tendency on behalf of outside players to view a community as a “collection of needs, problems...rather than recognising the community’s inherent strengths and existing resources” (Boyd et al. 2008). The following steps in the ABCD process are to be considered in the design of the community capacity building phase of this project:

- [Step One] Developing relationships within the local community and ensuring inclusion of the most marginalised groups.
- [Step Two] Identifying the networks within communities- individuals, groups, agencies- who can contribute to the initiative through asset mapping.
- [Steps Three, Four and Five] Expanding the identification and asset mapping of stakeholders and creating partnerships between these groups (Boyd et al. 2008).

All of the above approaches are characterised by a shared a commitment to building on the identified strengths and opportunities available in local communities, and working at a local and community level.

## **Capacity building frameworks case studies**

Two examples of frameworks developed for building capacity in early childhood health promotion and broader capacity building to improve health, illustrate lessons to be considered when developing this project's framework tool.

The first is a framework introduced by the Harvard Centre on the Developing Child in collaboration with the Women's and Children's Health Policy Centre and John Hopkins Hospital (Mistry et al. 2012). The pathway through which the creation of policies and programs that build on the capacities of family and community result in the foundations of health required by children to build biological mechanisms and healthy development across their lifespan.

Of interest to this research is the breakdown of family and community capacities that were identified as important when developing programs to improve child development, with the focus on family and community playing a central role.

Family capacities were grouped into four categories:

- Financial resources - this is associated with the fewer resources available to families living below the poverty line.
- Time investments - the amount of time available to a family to spend together has a correlation to health outcomes.
- Psychological Resources - the ability to meet parental demand and hence the quality of parent-child interaction and the link between mental health and adverse child outcomes.
- Human Capital - translating to skills which can leverage employment, the most common being educational attainment with theoretical modelling that shows educated parents earn higher incomes. Health literacy is also a factor and defined as the “capacity to obtain, process, and understand information needed to make a health related decision” (Mistry et al. 2012).

Community Capacities were considered to affect early childhood health in two ways:

- Institutional Resources - an example given was parks, with the physical features providing parents and children with opportunities to interact. However parental conceptions of safety and playground characteristics affected the impact of this resource.
- Collective Efficacy - the ability of communities to build social networks informally in the community based on trust and common values. It emphasises not just those networks formed and how these operate in the community but also the function of “social control mechanisms...including monitoring the behaviour of others and supervising children” (Mistry et al. 2012).

The second framework “A Framework for Building Capacity to Improve Health” (NSW Health, 2001) purpose is to guide the development of effective capacity-building practice within health promotion. This framework identifies the following key principles of capacity-building practice:

- Respecting and valuing pre-existing capacities - with a focus on exchange of expertise between groups and the sustainability achieved through integrating programs into existing structures.
- Developing trust and respect - imperative to capacity-building and demonstrated through meaningful engagement, communication and consultation.
- Responding to context - the range of physical, economic, political, organisational and cultural contexts.
- Avoiding pre-packaged ideas and strategies - capacity building to be viewed as an approach with a need to work across key action areas with a variety of approaches.
- Developing well planned and integrated strategies - working at a number of levels, with individuals, groups, or organisations and across areas of organisational development, workforce development, resource allocation, partnership and leadership (NSW Health, 2001).

# 04 Methodology

## How we went about it...

Families of the children in the target group were approached over a period of 6 months to take part in the research through a varied recruitment strategy including:

- Information circulated in hard copy and via email through established networks of child and family services
- Use of project partners and reference group networks for promotion
- Invitations delivered to preschools and early childhood centres across the region
- Flyers posted in community locations including shopping centres, doctors surgeries, libraries, swimming pools, youth centres etc.
- Promotion of the project in local print media and on local radio and community events
- Engagement with local service providers at staff meetings and interagency meetings to explain the research process and seek referrals, and
- Requests for participants to refer other families to take part in the research.

Some challenges arose with recruiting families for individual interviews and feedback was received that in some cases families were very busy with day-to-day activities and were not able to find time to commit to an interview. Those individual interviews which did take place were received largely through referrals by organisations that had established strong relationships with families. Other feedback was received further along in the recruitment stage that the use of language, specifically the word 'disability', would be confronting for some families. As such language was changed in all communications material to the term 'additional needs'. Service providers suggested this could be the case particularly for families who had yet to have their child diagnosed or were in the recent stages of this process which is commonplace in the 0-8 year age group.

A strategy was developed to overcome the initial challenge with recruitment and two family days were held, where children and families participated in a group process. This was used with two groups highlighted as having less representation in the individual interview sample - Aboriginal families and dads, grandfathers and their partners.

Families who took part in interviews received a \$30 gift voucher and each child and sibling were gifted a book in thanks for participation. Participants at the family days also received a gift including gift bags, and a lucky door prize.

Individual interviews involved children and the researcher together drawing a pictorial map which represented the child, people and places which were important to them, and conversations about these people, places and relationships. Once the map was complete, we asked the child to put a star sticker on the place most important to them, and a heart sticker on the person most important to them.

More traditional individual interviews with family members followed the mapping process with children, in which family members were asked about the qualities they loved in their children; whether others saw these qualities; about the kinds of connections the child and the wider family have; and about what they feel helps their child and their family to feel a sense of belonging in their community.

The group process involved families and children working together in pairs to draw the maps, followed by organised activities for children and families. A group map was developed during this time by the group facilitator which was representative of the individual maps. This was used as a focus for a group discussion with family members, while children had supervised play activities.

The families reported the mapping process with children to be an enjoyable experience, with many children opting to keep their map. The group days worked well as an option for families with whom an individual interview was not appropriate, and provided a forum for speaking about the systemic issues experienced by families at a community level as opposed to discussing personal situations.



## Report Structure

This report aims to give voice to the kids and families who took part in the research, while maintaining their anonymity. All quotes provided are from the interviews and group discussions with parents, except for the children's comments which are noted. Parents gave permission for maps to be used in the report with all identifying details removed. The children were asked to provide a pseudonym to be used when quotes made reference to their names. Overall, the use of language has been considered so the report is accessible for all stakeholders that the project outcomes will impact.

## **What we asked kids and families**

The following questions were used as a guide in the interview process.

### **Kids mapping exercise:**

1. What places do you go?
2. Do you go there a lot?
3. Who is at these places with you?
4. What do you do with the people at these places?
5. Which places (star) and people (heart) are the most important?
6. Is there anything else you would like to put on your map? Is there a reason why you can't put it on there?

### **Interviews and group discussions with families:**

1. Are there any things you would like to say about [your child's] map?
2. What do you love about your child? Do other people see these qualities in them too?
3. Can you tell me about the kinds of connections that you see that your child has?
4. What places/activities/relationships?
5. Can you tell me about the kinds of connections that your family has? What places/activities/relationships?
6. Does your family have a lot of community connections? Are there any things that make it hard for you to make connections with other people in the community for your child or your family?
7. What helps your child and your family feel like you belong in your community?
8. What makes it hard?
9. What would make it easier?

## **Data and analysis**

We transcribed 11 individual interviews with children and family members, and analysed the written material by drawing out the common themes.

In total, we gathered 31 maps from children during the project. The places, people and where possible, the relationships between places and people, were also analysed. This was done by naming the images in a table and identifying the shared themes which were common to a number of children's maps.

The group processes were audio-taped and detailed notes taken of the key themes and issues discussed in the group sessions. Group mapping was used, and concept mapping was used in one session as a form of note-taking to track the discussion. These records formed the basis of materials for thematic analysis of the group discussions.

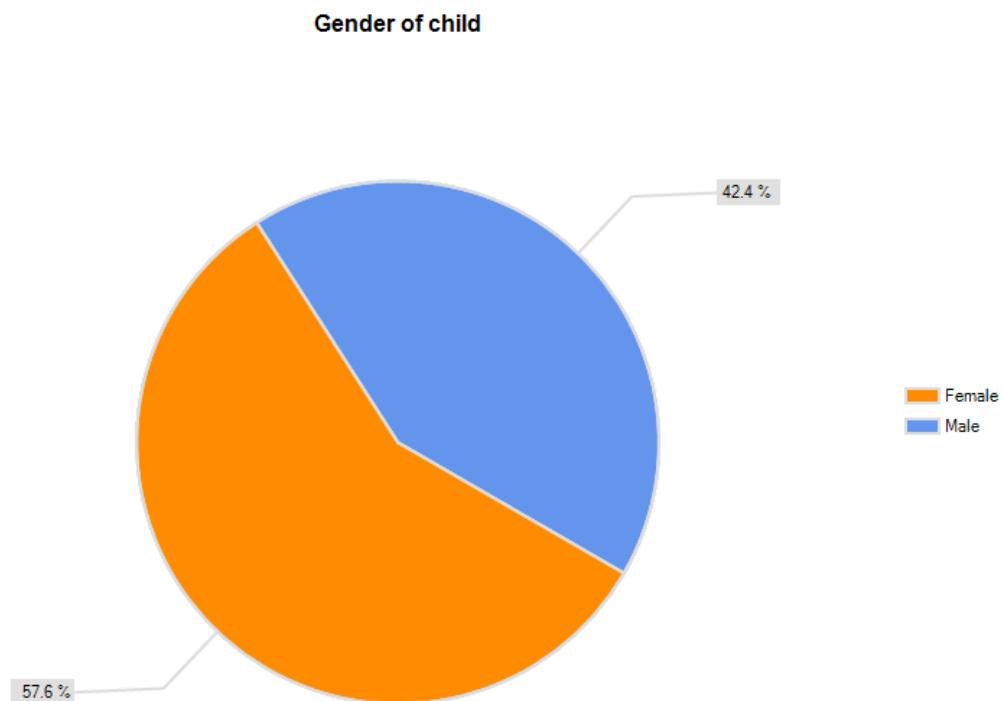
The research team cross-checked each other's analysis for reliability, and discussed the early emerging themes with the reference group.

# 05 Demographics

## Who we spoke to: numbers and figures...

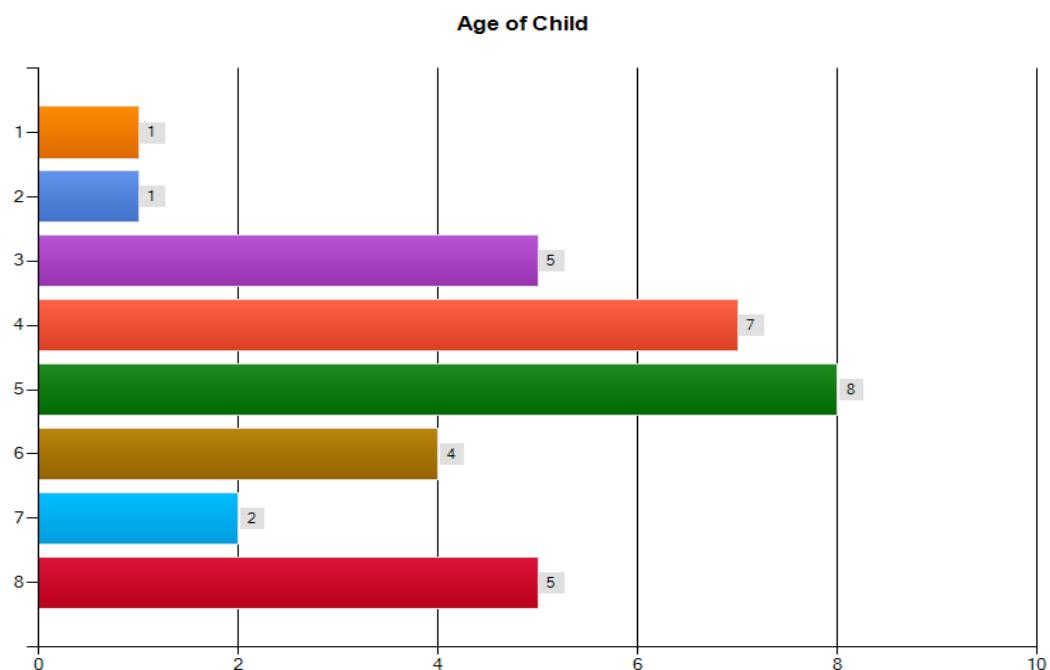
A total of 11 individual interviews and two group interview processes with 33 children and 40 parents took place, with demographics being recorded across a number of areas. A summary of key features is as follows:

### Gender



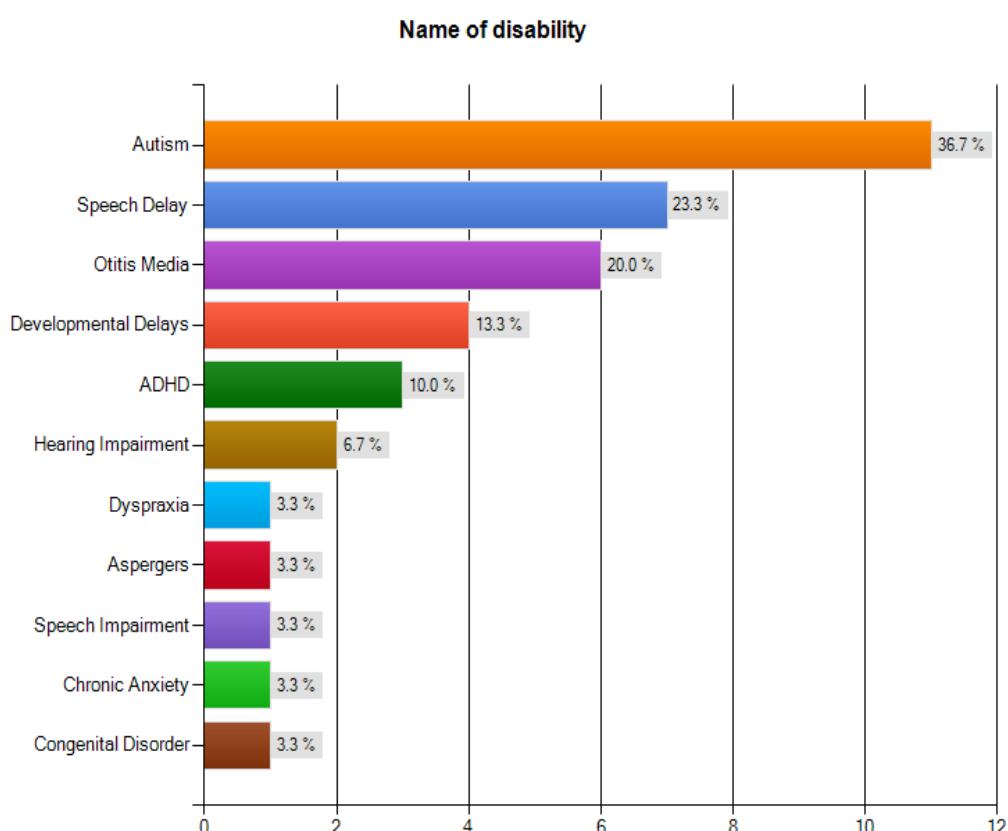
There was a relatively even spread between the number of male (42.4%) and female (57.6%) children who participated in the mapping.

## Age



Representation took place across the spread of ages from birth to eight years of age.

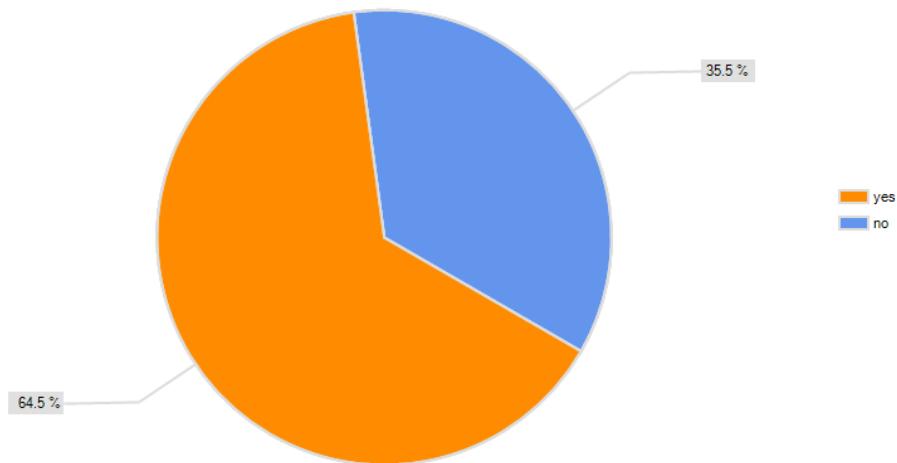
## Name of disability



Children with autism made up over a third of the children in the research.

## Siblings

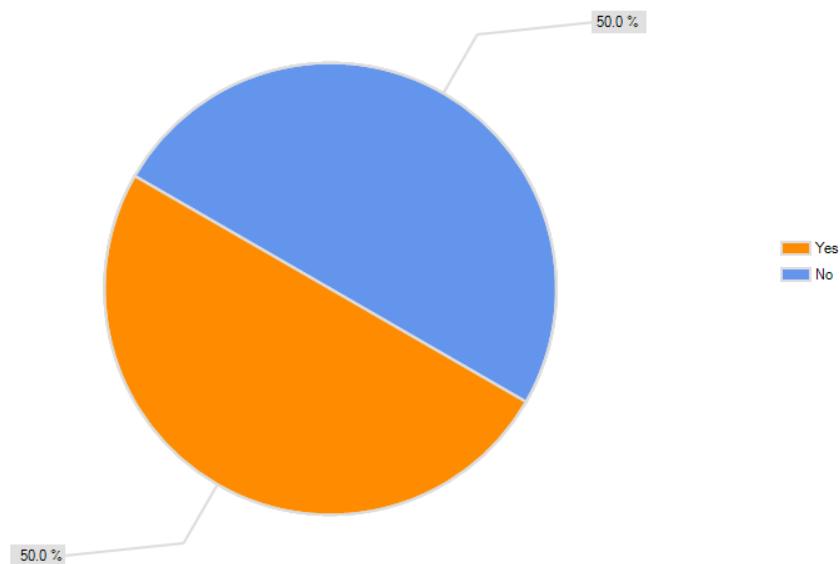
Siblings with disability?



64.5 per cent of children who took part in the research had a sibling with a disability.

## Aboriginal and Torres Strait Islander Families

Aboriginal and Torres Strait Islander Family



50 per cent of families in the research identified as Aboriginal or Torres Strait Islander.

**Who we spoke to: parents tell us about their kids...**

**“I don’t see him really in terms of his disability, I just see him.”**

**“He is my life, he is funny, smart, he is a great big brother to sister really caring to her”**

**“She is very independent, she doesn’t sway easy she knows what she likes...She is funny and loves to sing she is always singing, her creativity, its always good to see what she is creating”**

**“I love his tenacity and his quirky aspect of life, he surprises me all the time.”**

**“...she is just very colourful, talkative, out there, very loving and affectionate and has a very good sense of humour ...I just love the way she always sees good in people.”**

**“He is always happy and always has a smile on his face, he is just so cruisy, with his speech it doesn’t worry him, he doesn’t mind repeating himself, he is just a happy kid.”**

**“Her big smile, her determination to get there... everything that she does you just kind of marvel it although it is just becoming a normal kids stuff.”**

# 06 Outcomes

## What kids and families told us about what's important to them

### Places: beaches, rivers and parks

Many of the places children described going to were outdoors - parks, beaches, the river - where they played on equipment, ran around and generally enjoyed the open space. In the children's maps, these outdoor places were represented more than any other places combined, appearing over 30 times in 26 of the 31 maps.

Sometimes children talked about going to the beach, river or park with friends but mainly these outings were with family. In some cases parents explained that the outdoor places were chosen so there is minimal social interaction with others to avoid anxiety and meltdowns, thus allowing kids and families to enjoy themselves:

*"He is just completely free in himself at the beach - just wild abandon, it's beautiful to see him in any wild space, and he's always been like that."*

*"I like the park, the swings"* (Child)

**More than  
75% of kids  
put the river,  
beach or park  
on their maps  
as a place they  
like to go**

Aboriginal families spoke about the reasons their Jarjums enjoy being out in nature:

*"All those places they are places kids can all go, they can go there and run around, nobody's going to say 'that kid's screaming', or 'look at them, they are unruly'- no, look at them they are having a good time running around. They are out in the community as well, being part of the community, being accepted for who they are, and what they are, and their culture, and being proud of who they are, and not isolating themselves by not just being home based all the time."*

### Places: early childhood settings, early intervention and school

Parents talked about early childhood settings and early intervention places as a trusted means for receiving information and knowledge.

*"If they give me something and say this event is on in the community then I know that it will be ok if I go."*

School was discussed as an important place for inclusion and is often the first mainstream setting kids and families enter once stepping out of specialist support from the early childhood sector and early intervention. There was much anxiety about this transition process for families and the importance of good communication between parents and school staff was clear.

*"A bit nervous, probably because they don't tend to like taking kids with special needs."*

*"If you communicate with the school, that's been a big thing, they have been really supportive."*

### **Activities: hobbies, culture and sport**

Several children took part in swimming, karate, football, dancing and horse-riding. Interestingly, these organised, regular activities, did not appear very frequently on children's maps.

A small number of parents spoke about the positive impact these activities can have for kids,

when these places and organisations are inclusive and understanding of kids' needs. However, when such activities did work, it was as a result of instructors listening to parents' advice about how best to assist kids to take part. Then parents report an increase in self-esteem as kids make friends, learn new skills and form a sense of self-identity based on this connection and belonging. Furthermore parents report that their own sense of belonging was confirmed and strengthened.

## **“When you do find something that works for your kids it’s like winning the lotto”**

*“My two eldest they do horse riding, the women who runs it has no experience in ASD but she gets it and gets the kids ... it's just fabulous for the kids, for their stress and the self-esteem because they are getting better and better, they go from walking up to cantering and it's the exercise and getting out in the sun and feeling positive about themselves because they are doing something. I know with my kids, when they go to school they talk about it because they are proud, it's their thing, they get to talk about something they are doing. It's a struggle to find an activity where you can feel that sense of belonging that you are connected to outside because it is very, very easy to get isolated and not have that connectedness to that outside world.”*

*“The kids were going to gymnastics and the teacher had done one of Aspect's courses ... She said whatever his behaviour is, he is always welcome; you don't have to not bring him because you think he is fragile. We'd walk in and she'd say 'ok- he is delicate' and would relax what was required of him. It made me feel like when they are difficult I don't have to hide away from the world and pretend we are not here, I could actually be in the world anytime.”*

Culture Group and the Jarjum's (My Time) Playgroup are important places that Aboriginal kids drew on their maps and that their parents highlight as an important place for both of them to go.

*“...the My Time playgroup, I feel like part of the community... that's where I feel like I belong because it is more with my culture. It's good because all of the mums are great to talk to and we all feel at ease because we don't feel judged there..”*

*“I'll be honest, culture comes before school.  
Learn your language.”*



### **Relationships: children**

Many of the children put their pre-school, family day care, supported play groups and schools on their maps as places they liked to go. They did so in relation to the friendships with other children they formed in these places and the activities they liked to do there. These educational settings appeared on over a third of all the kid's maps. Parents commented that it is in these places that kids get a chance to interact with their peers:

*"It's interesting because all his social outlets are through services, so is interesting seeing that it [his map] is more focused on services than actual social groups..."*

Children drew places on their maps where they enjoy the activities that take place and the people with whom they participate. Drawings of therapeutic places were absent except for Early Intervention and here the pictures always involved their friends. Whenever school appeared it was also with reference to kids' friendships. The beach, park and river also were depicted involving boating, fishing, swimming, playing.

*"It is my kindy - I go there by myself...I don't like kindy though, but I like to go on the slide..."*

Parents also discussed that while forming friendships is often difficult, when kids do make this connection it has a positive impact on their wellbeing. The opportunity to establish friendships occurs for some kids while taking part in activities with other kids.

*"Sarah loves Claire, always wants to be partnered with her, she is an older girl who is really nice to her and all the other girls don't pay much attention to her. When Sarah first started Claire was really nice to her and helped her with positions on the barrels and she was really drawn to that."*

*"...he has had no friends, we have struggled... no social group but what has happened is that he has gotten onto this x box live system ...the changes in him, he is on there and is connecting with these children...playing this minecraft and they are talking away. I went in there and there was a voice coming out of his x box and he said this is my friend. His first ever friend, and the change in him, rushing home and he wants to get on there, his self-esteem – [he says] 'I feel part of it, he's my mate'."*

**"The  
family unit  
to us is a  
really,  
really  
important  
thing to  
have that"**

### **Relationships: children and family**

The relationships children have with family members, both with siblings and extended family, are a key feature of how they understand belonging and connection. In interviews with children and family members, visiting places and spending time with the family as a unit featured prominently for almost all participants. This can be seen especially clearly in the drawings on kid's maps depicting (in over one third of the maps) parents, brothers, sisters and cousins at outdoor places and other family member's homes. Nan and Pop's and Cousins' houses feature and kids placed hearts on their drawings of family members in over half of the maps.

*"The bulk of our extra people contact would be our siblings and their kids."*

*"The family unit to us is a really, really important thing to have that there"*

The importance of having time together to enjoy each other's company in a pleasant and fun way was a priority for parents and, while this was not always easy to achieve, parents persevered.

**“...at the end of the day you just want your children to be happy.”**

*“We spend hours each week with this service or that service and doing therapy and filling out forms, the typing it all up and drawing it up and printing it out and having family meetings and saying now we are going to do this. It’s like where is the fun? I think fun should be implemented as therapy. It’s hard often to play with these children so maybe we need help learning how to play with them instead of learning how to read them and teach them and instead learn how to play with them.”*

*“We did actually go on a holiday a few years ago overseas believe it or not...it turned out to be the best thing we ever did. We had an absolute blast and we had a few challenges...we got to have fun as a family and that’s really hard for us to do that and seeing the children have fun because with Asperger’s, my husband and I say it’s not the learning disability, it’s seeing them have the melt downs and the anxiety and the sadness because at the end of the day you just want your children to be happy.”*

### **Relationships: Parents**

Parents discussed the importance of those relationships that are able to be maintained whilst caring for their kids.

*“Before I moved I had a few people who would tolerate all of them on occasion but we were much better friends...if I had neuro-typical children I would be meeting up every weekend to do something but now it is more like bi-monthly. One friend in particular she really tried to understand and tried to help and do things in the right sort of way to get the results.”*

Parents also talked about the importance of the relationships they build with other parents through groups and activities based on a common understanding of their kids and parenting responsibilities.

*“It’s interesting, at the Positive Partnerships workshop, I was saying to my husband that was one of the first times I was in a room with people who understood what I was saying. I have a lot of friends but there is a difference with people with kids on the spectrum, because it is not a visual disability.”*

*“The Shaping Outcomes course, it is the first time that parents have been able to sit down with other parents of children with disability ... It is just once a week for six weeks, and trying to connect with other parents, it has been awesome we have felt like we have friends.”*

## What makes it hard for kids and families?

### A lack of understanding and inclusion by community organisations and businesses

Parents and children seek out activities and places to go where they can build their connections with the community, enjoy time together and socialise with other families. They did, however, discuss barriers faced when doing so. In many instances parents talked about negotiating the needs of children, with instructors and organisations, so kids could take part in activities in an enjoyable and meaningful way. Many of these requests were successful and implemented positively. However some families reported having difficulties with getting instructors/coaches to understand the needs of their children.

*"I tried my son with an AFL team last year because he loves sport, but if he didn't score a goal he would cry because he is over-emotional and we are still dealing with that. Then the instructor just kept getting frustrated because he just saw him as this boy who was soft and weak. The crying and the looks and he was saying 'come on toughen up' and we tried to explain about the thing, but he is only in kindergarten"*

Families also reported being forced to move their children out of a service or activity due to being pressured about the added support needed to include their child.

*"School holidays are terrible for me and the stress on the people that were looking after the kids was difficult as well because they don't get the opportunity to play with the other kids, because the coordinators find it too hard. So they say 'oh we can't discriminate against you, of course your kids can go' but they still make you know that it is difficult for them to have the kids so that puts pressure on you as a parent."*

*"Our son was kicked out of pre-school because they couldn't handle him. This is a day care centre where they all have degrees, but when it came to my child they could not handle him, they could not have him included in the class. They could only have him if he was alone somewhere by himself."*

**"We don't go to the play centre in Tweed because he can only handle about an hour and they are not very understanding when he has a meltdown. We drive the whole way to Robina, because if we need to, we can go out let him calm down and then they give us a pass to come back in. They are very understanding of the fact that he has autism, and we took 10 children there for his birthday, right in the middle of the day and they were happy. They said alright we can turn down the lights in the disco if you need it, they were more than happy. We will drive an additional half an hour up the freeway, just to do that."**

### **Financial barriers to belonging**

Parents talked about the cost of therapies and other activities needed for their children to grow and learn in a healthy way and the issue of affordability in meeting this for families.

*"We've done quite a few art courses but we have to pay for that, I take them up to creative arts at Burleigh but that costs \$100 each time I take them up there, it's expensive and I don't have that kind of money to be spending on art every time."*

A further factor is the costs associated with activities and transport to and from places and activities.

*"We've got some big families and that restricts them what they can do financially and they have to prioritise do I pay this bill or get the shopping, everything is so expensive."*

Finances also place stress on families when it comes to paying for medical bills and expenses.

*"The FAHCSIA funding- it stops when they are seven- he is nearly seven and he still sees the psychiatrist at \$140 a pop, if she comes and does a school visit it's \$300 and that comes out of my pocket. We can't go on camping trips, we have a mortgage to pay and bills..."*

**"I can never relax and just sit back and have a cup of coffee and not worry about how the kids are not coping"**

### **Barriers to participating in the community**

Many families discussed that while spending a significant amount of time together as a family, they do not have many other connections outside of this unit. Parents spoke about the difficulty of having connections and socialising with other families due to a lack of understanding or acceptance of their children's behaviour.

*"Getting invited back to barbeques, one of the kids will have an issue with something and how society and that works - you can come as long as you leave child A at home, or you can bring child E, C and D, kind of thing."*

The impact this has on the parents is apparent and was talked about in terms of not being able to relax and spend time socialising when out as a family.

*"There are only a few select friends that we can interact with their kids, but still I can never relax and just sit back and have a cup of coffee and not worry about how the kids are not coping."*

Parents talk of the challenge that time constraints places on a family's social life:

*"We would love to foster relationships with other families, like through early intervention but the thing is that you are all in the same boat, you are always so busy taking them to this therapy or this service and you try and arrange something with parents from a group and you struggle to get there. When you try to create opportunities of togetherness within the group of early intervention it is a challenge because of all the things that are going on personally in those families. You might actually be able to achieve that end result with families who are not going through all that stuff."*

Families also spoke about the challenge of being able to find one-on-one time with a particular sibling, or time off as parents to go shopping, attend appointments, and have respite.

## Even going and getting a haircut, that is a big challenge to us.”

*“We don’t go out and do anything in particular, it’s very difficult. Peter was getting respite but now his younger sister has arrived we can only get it for Peter, so there is nothing we do as a family other than that. It’s just too hard because we don’t get respite for her - it’s just too hard, we don’t get a break. Either his dad takes him somewhere, or I take him somewhere- we don’t go anywhere together.”*

Many families in the research have more than one child with additional needs and this has a compounding effect on their ability to attend places, activities and events as a family.

*“So going out for us is really a big challenge because it depends on where all the children are at on any given time. Even going and getting a haircut, that is a big challenge to us.”*

### A lack of appropriate infrastructure and amenities

Finding places that are accessible was raised as a further barrier to children and their families making connections in the community. Accessible parks, built to cater for all kids and that are fenced were a major point of concern for parents.

*“Laguna park is good for him, he always falls over and the ground there is soft. To have steps which are smaller for kids, things that are wider, maybe a specially designed park somewhere..”*

*“If places were more disability friendly, that is, parks and different places. There was a really good park at Palm Beach ... we used to go up there because it is fenced off and it is disability friendly, we would all go there and we could get out and the kids could run and you’d know they weren’t going to go to the creek and drown.”*

So too, it is difficult for families to access events and services that provide appropriate support for kids.

*“They have a great play area and I want to have his birthday there, and they have a drop and dine facility, but he isn’t toilet trained... We can’t access the same facilities that the rest of the community can, because of those little things that a lot of people wouldn’t think about that. All the holiday places you go to, all the resorts, cruises, you can’t access any of those.”*

*“You can’t go to for example, the Australia Day BBQ. We had that this year and tried to go to that and that was a disaster. It was at Brunswick Heads in the park it was too loud, no fencing and that’s ok if there is not too many people but there were heaps of people and kids running everywhere and my boys just go crazy.”*

### **Community attitudes and behaviour: awareness of disability**

When considering the barriers to connecting socially within the community, parents overwhelmingly highlighted the judgement experienced from others about their kids and their parenting.

*"My skin is rather thick from many years of people looking and telling me that they just need a good flogging or a smack ...they just perceive it as naughty. So if you say you had a little toy or a doll you would be accused- oh your bribe didn't work. People would be in line in the supermarket and some people would say it to your face or would say it to the person next to them but you could still hear them."*

*"The practicality and obviously the lack of understanding and information especially with ASD, if I was to go through a shopping centre and my child was in a wheel chair and you get that empathy, but if I've got my child and they are having a massive melt down then people just interpret that they are just naughty and want a lolly and are being a little brat and that is a really big difficulty for parents."*

These comments, judgement and lack of awareness about kids' behaviours and needs result in parents avoiding community events and public places.

*"I would like to expose them to more things, parades, community things, like the movies that are outdoors but it would have to involve everyone having to put up with a scream for five minutes without punishing me for it, but just tolerance as well I guess."*

*"That's often why I don't go places publicly because the meltdowns can often involve violence, swearing abuse directed at me and directed at others."*

A key feature of being judged in public is the many strategies parents have developed to overcome the problems and practicalities of completing everyday activities such as shopping:

*"I would go down and buy shoes, bring them home, try them on and then take them back if they don't fit. There is all of that back and forth sort of thing, you just have to do that, it's easier.... I say to people get your groceries delivered... it's so worth it if you don't have to drag your kids there."*

*"I've got no one so if I want to go to the shops, we have to wait for Justin to come once a fortnight to do the home work and mind Simone and we run over to the shops for an hour. I wouldn't even take her to the shops, she runs off and it's just so stressful."*

**“By the time your child is 6 you’ve already got your doctorate of that child”**

#### **Community attitudes and behaviour: medical services and professionals**

Parents spoke about spending large amounts of time accessing allied health services with their kids, and reported that they had negative experiences with attitudes and behaviours from some professionals.

*“...GPs that understand it, that are willing to refer, that don’t make that diagnostic year so difficult and at least you know where they are because you can exhaust yourself trialling GPs, some of them even said I invented the symptoms because I wanted to get a pension.”*

This experience disempowers parents, who feel as though doctors do not value their knowledge, as parents, of their kid’s needs.

*“Even when you go to professionals, a lot of them don’t listen - they just go straight down the line how to deal with any situation and they think if you try putting that peg in that hole then it is going to work.*

*How long does it take to be a doctor - 6 years is it? By the time your child is 6 you’ve already got your doctorate, you know, the doctor parent of that child, and by the time you’ve got to 15 that’s an amazing time of study and experience and effort that you have put in, so parents do know because of that.”*

*“The doctors and the dentists they need to go and do more cultural awareness training in how to approach Aboriginal families, they make me feel like I don’t want to go to that service because they give you attitude. Doctors and paediatricians they even talk down to you when you go by yourself, they think oh she doesn’t know what she wants or what she is talking about and look at her kids - they judge and they shouldn’t be judging us in those circumstances.”*

**“You get a bit of shame when you are around professionals as well...”**

#### **Community attitudes and behaviour: discrimination and racism**

Families reported being exposed to discriminatory treatment which impacts on their sense of inclusion and belonging.

*“I had a pretty good corporate career up until he was about three years old which was when he was diagnosed and he couldn’t handle normal playgroups anymore- he’d got kicked out of three preschools so I worked from home.”*

Racism was experienced as a layer of discrimination that crossed several areas of belonging and connection for Aboriginal families. It is an issue that for many came as a barrier first before disability, and was felt through generations.

*“There is still a lot of racism in country towns, I moved up here ... thinking this would be a better place and be treated better and no racism and that, but it is still the same.”*

### **Communication and consultation between parents and schools**

Overwhelmingly parents report being frustrated with attempts to communicate with schools over learning outcomes for their children. The processes and systems for consultation and input do not meet their and their kid's needs.

*"There is a lack of communication there, I've tried and I've tried and it's like I'm hitting my head up against a brick wall and getting nowhere.... I'm paying for a good education, but really I'm not getting it,... rebel is a struggling student and I've been trying to get them to hold him back a year but no one's listening. I have meetings with the school teachers, the principal..."*

**... the  
education  
department,  
it's just too  
much square  
pegs for  
square holes  
and if you are  
a round peg...**

*"I don't have much faith in the education department, it's just too much square pegs for square holes and if you are a round peg...you've got to fit their mould, you've got to be able to tick a form ... some of them get it and some of them don't and you can't always choose to deal with people that get it and it can just be an exercise in frustration."*

Aboriginal families talk about having culturally appropriate strategies put in place to allow for good communication between kids, families and staff.

*"Shouldn't there be Aboriginal people at every school? Because I know when my son went to [school] I felt good that an Aboriginal teacher was there, to have that person to go to a black face instead of white faces... If something is happening in the class or the home there should be someone the kids can to go to that they all call Aunty - they should be made to have it. Didn't Kevin Rudd say sorry for a reason?"*

### **Streamlined and available information for families**

Parents talked about relying on word of mouth and sharing recommendations of places and activities that work well for children with additional needs. This happened in place of an established, reliable means of receiving information about a range of community events.

*"...[there is] a family day and then a siblings day and I'm on the mailing list and I haven't received any notice of this, I only know through the grape vine but they are the sort of things, that you can get support from your friends and family"*

*"There seems to be a lot of little things out there, I will be looking in the newspaper or at the community health clinic and there are boards with information and you think - should I do that? Or how should I link in with them?"*

*"I find that community doesn't network properly either - like one mob is organising something and if you don't run into them at Tweed City or something like that, you just don't know. They'll say we are doing this at Jarjums or we are doing this at culture and the other mob is doing this...and you find out about it after it has happened."*

## What helps kids and families feel like they belong in the community?

### Awareness and empathy from other community members

Despite the ongoing lack of awareness and empathy towards kids and parents, particularly in public places like shopping centres, when people in the community do reach out and offer support, families talked about this as having a positive lasting impact.

**“...just that one little gesture ... it gave me faith in mankind.”**

*“We were at Tweed City and he was having a melt down and he was a big boy and I was trying to carry him and he was kicking up against the shop window and everything is dropping everywhere and this lady came over and helped me and I burst into tears basically because she helped me... it was just that one little gesture that she did and it gave me faith in mankind.”*

*“The encouragement and recognition I get from ... various people you see that you’re starting to get to know and they will comment on how well she is doing and stop and say hello. At the mall or something and they come and give you a big hug and stuff.”*

### Connecting up with other families who have a shared experience

Parents spoke about the strength they gain and relationships they build from connecting with other parents and families who have a similar lived experience. This is based on a shared understanding not to judge the behaviour of children and how parents choose to respond.

*“He went to the social skills group at Early Intervention up until he turned six and started school ... and the kids and the mothers, we still catch up sometimes, for children’s birthday parties and things. Not only has he made friends, but I’ve made friends too which is hard when you’ve got a child with special needs, it can be hard.”*

*“There are a few families from early intervention - we have become friends. We have this unspoken agreement to not judge each other’s children’s behaviour, or parenting ability.”*

The relationships families do form with other families of children with special needs often occur through services such as Early Intervention. Although the role these relationships play more broadly in parents’ social lives differ, it is a common point of establishing connection.

*“I’ve got a friend a friend and our son met her daughter through Early Intervention...and I run into them at the shops, they are the only people I have contact with really. He has been diagnosed for two years now, your friends just drop away.”*

*“... We are the opposite, we don’t have any friends with special needs children, apart from Early Intervention and the mothers I see there once a week, we have no other interaction with people with kids with special needs and that would be something to establish.”*

The same benefits are reported by families when connections are made out in the community.

*“Claire’s teacher introduced me to one of the other parents who is the mum of an Asperger’s boy ... So the teacher paired me up with her and she was like ‘come and have a coffee, anything you need to know or if you need to talk about something or I know how hard it is, come on talk to me’. I thought ‘aaah, there is another person who knows what I’m going through’.”*

### **Proactive inclusion by community organisations and businesses**

Community organisations and businesses in the general community are sites outside of specialist therapeutic settings, where kids and families go to conduct their business, shop and socialise. When these places are proactive in creating environments where all kids can belong (a space of non-judgement, accessibility and catering for all sensory levels) this helps families immensely to enjoy their time spent out in the community, to feel connected, and to feel valued.

*"Tweed Bowling Alley is really good - Peter is having his birthday party there. They actually have a disability - bowling league... and because they have got that there they are really accepting of people with a disability, mental, physical or otherwise, so we, the whole family really enjoys going there because he can just belong."*

*"It's like going to the fireworks party, they are great. At Twin Towns, they put it on every year and it is for children with special needs and ...they have fireworks competitions and on one night of the fireworks displays, they would get everybody up in the top room that's got the glass so it's a soundproof environment for the kids to enjoy the fireworks, without the loud bang. Other times they have had it at Banora Point at the sister club, I've been there and they get a balloon guy and face painters and put on a heap of food and the staff and everybody there, nobody bats an eyelid at what the kids do."*

### **Education settings that cater for all kids' needs**

Preschools, early childhood centres and schools are all sites where adjustments can be made for kids to be included in a way that works for them. Parents talked about how this helps with kids' learning difficulties and allowed them to connect in their own way with their lessons and peers.

*"...this school was really good with kids on the spectrum and after meeting with the school twice I could see they were going to do everything to help her. They have a lot of good programs set up at lunchtimes and recess and things that kids on the spectrum can go to. They have drumming and they can go to the ipod club or they can go to the library and do something else, if they don't fit in, in the playground they can do activities. There is something on every day."*

**"the local pre-school, I would have to say they were extremely resistant at first but with the help of El...set it all up then they turned around and they are using it for all the kids. They saw the values of visuals and routine... Because one of the things he was doing was throwing a tantrum when music was happening, and we said it is just too loud, he doesn't like music, he doesn't like it. They said well he has to do music and we said well what else could he do, so then we worked with them and now there are other kids who also say it is so loud, so they can go and do art, they are all happy and they have come around.**

## **What would make it easier for kids and families? Strategies and ideas from families**

Families were asked what would make it easier for kids and families to feel like they belong in the community. There were many suggestions put forward which are built on the knowledge and experience of families and their drive to improve the quality of life for their kids. These included:

- Regular and structured meetings with schools for parents of children with additional needs to be empowered in the decision-making process over school spending of individual funding.
- A place for kids to gather and take part in activities that they are interested in such as craft, computer games, drawing - with appropriate professional facilitation and supervision.
- A homework club for Aboriginal children to access after school and use computers and get assistance with school work.
- More targeted information circulated through known networks about events and activities aimed towards children with additional needs and their families.
- Training and education for businesses, organisations and services that are in regular contact with kids and families to improve inclusive practice and responsiveness to requests from families when kids are excluded.

**“Maybe there needs to be a system to educate us how to educate others?”**

**“The mothers need training, what we really need is a business, a black women, Aboriginal mothers of the community entity...”**

- An awareness campaign, promoted throughout the community to educate about the needs of kids and how they experience the world and exhibit behaviours in public. This would include providing information on how to respond appropriately and show empathy for children and families.
- A hip hop program for kids to encourage them - they can see themselves on you tube as a proper film which is being shown to everyone.
- Advocacy skill development for parents to use in relationships with friends, interactions with people in public and negotiating with staff in schools and places where kids take part in activities.
- Training to build employment skills in developing work areas which support flexible work hours, such as individual and group support work for people with disability.



# 07 Implications: what is this telling us?

The views of children and parents about what makes them feel like they belong and are included in the community, along with the barriers and some strategies for change have been laid out in the previous chapters of this report. The experiences of kids and families are based on the places they go, the people they go there with, and the relationships they have, and this forms a framework for the following analysis.

## What does it look like when places and relationships work well for kids?

### Access to places and spaces

Physical access to places and spaces is a key facilitator of inclusion for kids. When access is possible and appropriate it caters for the needs of all kids. This is taking into account mobility, safety and ability of a range of kids and families. Parks need to be accessible with play equipment that can be used by kids of all abilities and ages, which have appropriate floor coverings and are fenced in - well away from major roads and waterways. If these factors are in place, parents are able to take kids to these community spaces and this allows them the freedom to run around, explore and socialise with other kids and families. Both kids and parents can enjoy themselves in a safe and inclusive environment.

**These  
small  
changes  
can make  
a big  
impact  
on places  
to make  
them  
work  
well for  
kids**

Similarly places that can make adjustments to their rules and policies, to provide kids with a space that works for them, result in opportunities for kids and families to get out and about. An example given in the interviews was of a child and family who were taking a trip by plane to visit relatives. What would normally have been a stressful situation, needing to pass through the security check at the airport, was abated by airport staff making a separate security gate available to the family. This allowed the parents to talk their child through the process of walking through the metal detector on their own, without having a queue of passengers waiting behind them.

Another barrier discussed by parents was the rule of many clubs and resort childcare which requires children to be toilet trained if they are to participate. The parents wished that this could be relaxed to allow them the chance to have a meal, or take time out on holidays, while their child could enjoy the activities provided in these services.

Only small adjustments would be needed to make this possible, such as ensuring a worker who was able to take one child to the toilet when needed and for this to be a sanctioned part of their work duties.

The aforementioned changes in practice both in small and large businesses do not take a huge amount of resources or time. These small changes can make a big impact on places to make them work well for kids.

### **The expectation on kids to conform**

Drawn from the many and varied experiences of children and families who experience judgement, criticism and discrimination in the community is the idea that kids are expected to conform to what is considered 'normal' behaviour.

Parents spoke lovingly about their children's many positive personalities and attributes, but commented that these qualities were rarely seen by others outside their family. In part, they felt this was the case due to the stress kids are put under when they are in environments that are not catering in an inclusive way to their needs. When kids exhibit behaviours which are not considered to be 'normal' - loud noises, movements, unexplained displays of emotion - other people do not know how to respond or understand in these situations.

*"The reality is that there is this expectation of what the norm is and all of us don't fit that normal box .... We hear a lot about community and trying to create that opportunity for people to belong ... They just don't understand, or comprehend or are prepared that there may be some experiences that are going to be out of their norm and they don't want to handle it because it is going to be too difficult for them."*

**"...some experiences are going to be out of their norm and they don't want to handle it because it is going to be too difficult for them."**

A parent described the difficulty of taking the family to a children's movie. This was due to other cinema goers' unwillingness to understand and accept their daughter's desire to move around the seats and be vocal. Other patrons would make comments and speak harshly to the child, resulting in the family needing to leave the movie early and the other kids being disappointed and frustrated.

When places do work well for kids whose behaviour does not fit the 'norm', parents attribute this to negotiation with staff members. One family spoke of the gym their child attends, where the instructor was willing to let their son come in and out of the class and activities as he was able, taking part in the way that suited him best.

The crux of this issue is to recognise that when kids are expected to always conform to 'normal' behaviour, this places the responsibility on children and families to 'fit in' to a community which does not make everyone welcome. The responsibility for creating an inclusive community more fairly rests with the community itself than with individual children and families who may already be living with significant pressure.

*"People's attitudes...it is normally from someone else who recognises autism or who has been exposed to it. Just an encouraging look or comment or something like that... sometimes in a shop when all the kids have knocked something or chucked everything out of the trolley and someone helped me pick it up, just little things like that, people being non-judgemental."*

As the experiences of children and families shows, small accommodations, acceptance, and recognising that children's behaviour is sometimes out of their control, can make big differences.

**"I think fun should be implemented as therapy. It's hard often to play with these children so maybe we need help learning how to play with them instead of learning how to read them and teach them and instead learn how to play with them...We spend too much time in therapy trying to change them and not enough time in just learning to love and accept them and to play with them and it has taken me a long time to realize that - I have missed out on so much fun here."**

### **Having fun and forming friendships**

As discussed earlier, children drew places on their maps in relationship to people and activities. On their maps kids also drew places where they enjoy the activities they take part in which are fun - swimming, riding bikes, playing at the park, on the farm. While these are activities and places which are regular rather than one-off events, parents also commented that the therapeutic places kids and families access on a weekly basis did not appear on any maps. Also the absence of shopping centres - places that parents told us the family would need to access regularly but cause distress for children - shows children's ability to represent their world and the places they like to go.

It is apparent that for these kids, connection with place is heavily based on the relationships they have established and the social interaction they enjoy. Kids put hearts and stars on those places where they have relationships with others and the places these are connected to. Friendships featured prominently and children were very proud to put these on their maps..."This is my friend...." This was particularly the case for older kids. Friendships for some children were rare, however, and at no point did children draw themselves at a friend's house, only ever at a place or activity.

The link between place, relationship and belonging for children becomes very clear in this context. Those places that work well allow kids to relax, be comfortable in themselves and for others to see this fuller representation of their personality.

The places children told us they like to go and the people they go there with were mainly family or friends formed through Early Intervention.

*"...people very, very close to him who see a bit of him like my sister, my mum, his grandma, but everyone would see his reaction to being in a social setting, they would see his anxiety, not his personality. I think at early intervention they saw him and that's why he liked going there."*

*"At home it's ok because this is her space but when you're elsewhere that it's a lot harder for her to interact with people that she doesn't know."*

While some parents spoke about difficulty with extended family members, for most it was family who understood their children and were able to relate well to them. As such, it is important to recognise that wherever possible, kids should be given the opportunity to interact with other kids and to have fun whilst doing so.

Activities designed to engage with kids and families work well when they have play as the focus. The design and management of places further needs to allow for kids to explore their common interests with other kids, and to promote their strengths in the public domain.

## **What does it look like when places and relationships work well for families?**

### **Parents are consulted and listened to in a meaningful way.**

Incorporating parents' knowledge of their kids' needs to modify and improve practice have resulted in more inclusive places that work well for families. In the experience of families, it is when parents are listened to and their advice taken on board that positive changes are born.

*"The first class I sat at the side of the pool with the teacher to help her come up with ways of helping her. Then the second class we are going to try with me not being there so they can try and work it out... She has just started swimming lessons two weeks ago, she is in a small class with younger brother and two other children, and it is just a half an hour class, it's a smaller one little pool indoors so it is bit less overwhelming than the public pool..."*

School is highlighted as a place that works for families when there is willingness on behalf of teachers, principals and staff to have open communication. Ongoing and meaningful consultation requires established methods that work well for kids and families. Parents' skills and initiative to build their own methods of improving communication between parents and teachers also need to be recognised. Several parents have developed resources for teachers based on their kids' needs and what works well for them in a learning environment. Other arrangements have been less formalised and are based on respectful relationships and a commitment from teachers to look out for the wellbeing of their students.

*"We have an arrangement where the teacher text messages me to give a heads up before he walks in the door that it's been a difficult day..."*

It is evident that a mix of both formal and informal strategies for communication and consultation with parents in a number of community settings can contribute to positive outcomes for kids. Some parents have the skills necessary to advocate in this process while some others do not. What is common across all families is that parents are experts when it comes to their children and will be crucial in any community development process.

**“...they need to listen to us more ...this is what we need, is this possible, if not why not, how can we fix that.”**

### **Autonomous Parenting**

A key feature of places that work well for parents is their ability within this environment to care for and parent their kids how they choose and in a way that works for them. Parents have a responsibility to care for their kids' safety and well-being and this can be compromised when places are not inclusive. A park that is not fenced or is near a road or waterway, does not allow parents to take kids there to play without a risk for their safety. Parents also describe the beach as a place where they can go and kids can run free. In this situation parents don't need to worry about unexpected or forced social interaction which may cause difficulties. Hence it is a space where parents can choose to operate in a way that is going to suit them and their kids.

Similarly, when public events are designed and promoted as being inclusive, parents can attend

with the knowledge that kids will find it easier to cope. This takes away from the responsibility that parents have to make sure that places are suitable for kids and for the parents to take care and keep an eye on them there.

*"...you become locked in this world of people don't understand and you become defensive and a bit like you are hugging your children in this big circle and are being overprotective because you don't know what type of reaction you are going to get from people and it's hard."*

The issue of people judging and making comments about parenting also comes back to allowing parents the right to manage their child's behaviour in the way that will work best for their family.

*"We were at McDonalds and he started to have a meltdown so my partner and I just walked away and left him. We knew that if we tried to calm him down it would just escalate things...the looks we got from other people"*

## **“There is not enough focus on the dynamics of the family”**

### **Family Cohesion**

Throughout the research themes, it is clear that parents are the key facilitator of children's belonging. When parents have places they can go, and relationships that work for them, kids benefit by also going out into the community and building their own connections. As with kids, the connections between places and relationships for parents are intrinsic and intertwined. The dynamics of a family also plays a large part in considering relationships for parents. The opportunity to build cohesion as a family must take into account the other sibling's needs. Many of the families in this research have more than one child and each has their own needs. It is difficult for parents when respite and support is directed at individual children and does not allow for siblings to take part.

*"There is not enough focus on the dynamics of the family and taking that into consideration...One child had the opportunity to take part in surf lifesaving up the coast, but because the other children couldn't participate I had to get someone to care for them so I could support him and support him but the other children had to just sit there and watch."*

On the positive side, when a sense of identity is established and belonging is felt by one sibling, parents report a ripple effect is felt across the family as tensions die down and kids are happier.

*"...now he can't wait to get to school, to see his friend and it's giving him that common interest. So it has a positive impact on him and that rolls onto us as family and our life and how easy things become for us."*

The size of a family and the associated costs with caring for multiple children affects families' ability to enjoy outings and time spent together. Assistance with transport and financial support would allow for parents and kids to spend more time out in public, establishing relationships amongst themselves and with the broader community.

*"Transport is a big thing, you've got to risk taking Jarjums in cars without car seats, and making sure you are not overloading and doing four or five trips just to do a day out."*

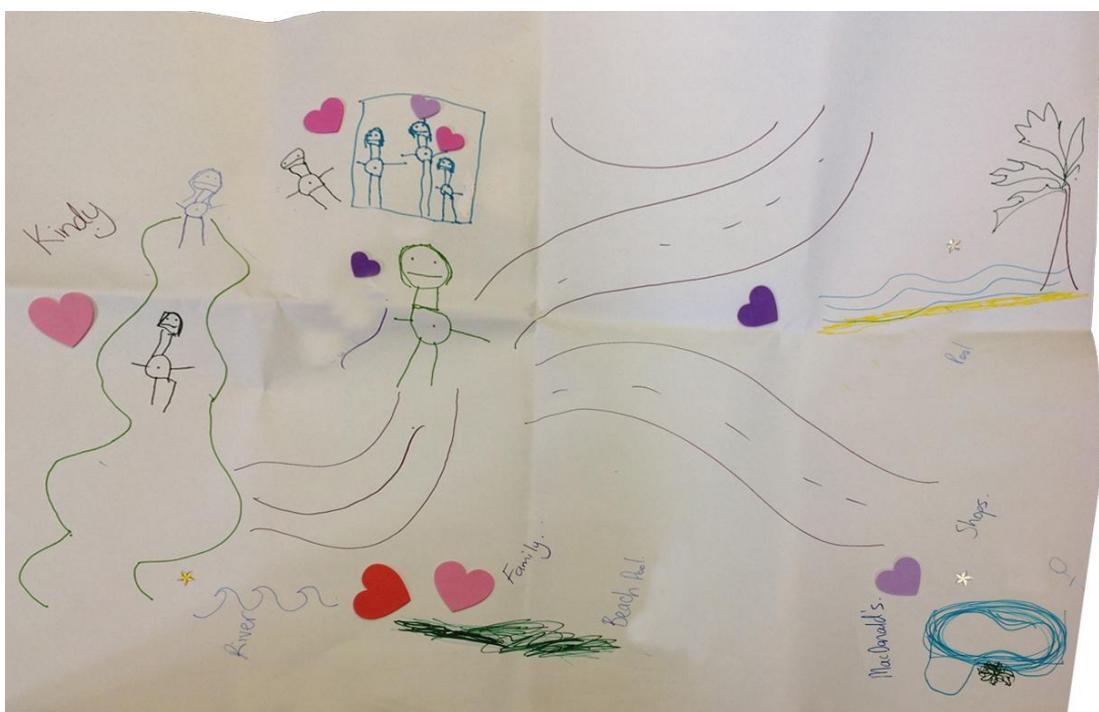
### **There is no norm when it comes to kids and families**

Finally addressing the expectation placed on families - that kids behaviours fits the norm - could significantly improve belonging and inclusion. For kids, the impact of impairment in the study was seen more through restrictions to *place*, with them not being able to access places for their safety or to prevent potential distress. For parents, *relationships* were more affected, and most family members who participated in this research talked about the impact of feeling judged and criticised for their parenting, and excluded from complete acceptance and community membership. From comments by family members, to strangers in public places, to managers of shops and school staff - community awareness has to be improved. Education of the wider community to take responsibility for inclusion at all levels and to show empathy towards children and parents will go a long way to fostering a sense of belonging.

At the same time, the experiences of kids and parents differ within and amongst families and communities. Parents spoke of the many barriers kids and parents face to belonging in the community, preventing often the opportunity to take part in many activities in a range of places. Children did not represent these challenges on their maps, instead representing the positive interactions. This is most probably linked to their age and the question posed – “where do you like to go?” However this highlighted the contrasting perceptions of belonging and connection between parents and children.

Another illustrator of diversity in the lived experiences of children and families was, although many shared similar experiences, there were always different options that worked for families on one issue. While a majority of families may have accessed the supports they needed, the one or two who had not were at a serious disadvantage and revealed the gaps in some processes that failed to include all. On the flipside, individual families have developed unique and insightful strategies that have improved their lives and these could be built upon by acknowledging and sharing this innovation with other families.

It is important to reinforce that the one size fits all approach does not work for children and families. Options and choice must be exercised for children and families to genuinely find what is right for them.



# 08 Recommendations: Building Blocks

The experiences of children and parents form a foundation of values and principles on which to build a model for strengthening capacity. The following building blocks form this basis for successful and inclusive practice to happen:

## **Taking note of what is important to children**

The positivity of expression, experience, and perspectives of children who participated in the study were strikingly different to the experiences of older people with disability. In part this is because they are young, but in part it is because they are growing into a more inclusive world. Research, policy and practice should take a lead from the positive experiences children enjoy and build from their expressed desires.

## **Responsibility for inclusion rests with the community**

Kids and families should not be expected to be the ones who change in order to be included in a community. Building inclusion can occur at many levels by community members - from small personal shifts in attitude and showing empathy - to relaxing rules and rethinking the design and management of organisations and businesses. There will always be something everyone can do to make lives easier for children and families and share the responsibility for building an inclusive community.

## **Sustainable activities within families resources**

For capacity-building strategies to be inclusive, opportunity can exist for those parents who are able and would like to contribute their time. Reflecting the time poor nature of many families in this research however, capacity-building should not require additional time and resources on the part of kids and families. The process must be one which utilises existing resources and skills within families and focuses on developing these in a sustainable way.

## **Relationships are key to connection and belonging**

Kids showed the importance of establishing real friendships with other kids and this happened when they were able to take part in fun activities, whether socially or for therapeutic purposes. Parents consistently affirmed their desire to focus on building relationships, both with family and friends. This relational process also includes developing, building and sharing strengths, capacities and resources.

## **Parents facilitate belonging for kids**

As for all children, the parents of children with disability are the key facilitators of their engagement with the wider world. However, for kids with disability and their families, the negative experiences, stigma and discrimination that many families described have a very significant impact. At times, this affects the way that kids and families feel they belong to their communities. Providing skill development opportunities to families in advocacy, raising the awareness of the wider community to diversity, and resourcing spaces, activities and relationships are all ways in

which these key relationships can be supported and sustained

## **Meaningful consultation with parents**

Recognising and acknowledging that parents are the expert when it comes to working with their kids is paramount for services and professionals. Parents have the skills, knowledge and require an opportunity to share these with the community services and education sector. However, consultation and participatory planning needs to be conducted in a meaningful and culturally-appropriate way for parents.

## **Belonging begins with ‘Closing the Gap’**

Aboriginal families report racism and discrimination across the community from a range of sources, including other parents, doctors, and schools. These experiences amount to a real and devastating compound disadvantage felt by kids and families. Yet parents we spoke to showed resilience and passion for closing this gap in opportunity for Jarjums. This strong connection to culture and country is an asset to acknowledge and build.

## **Parents know what is best when caring for their children**

Parents have to be allowed to provide care in ways that work for kids without being subject to judgement and abuse in the community. Education and training must occur with businesses, organisations and the wider community to build understanding of what life is like for kids and families and methods of engagement to foster inclusion. This can also be supported by provision of accessible playgrounds and community events designed to be inclusive i.e. are promoted on flyers as being an appropriate setting for children of all abilities. That way parents can bring their families without concern for their welfare and know they can care for their kids in this environment.

## **Inclusion starts at home- supporting the family unit**

Keeping kids at the centre of planning must be the priority; however taking into account that the siblings and other family members make up the dynamic of the family unit is key to inclusion at home. Where possible the whole family should be considered in respite opportunities and providing families with access to financial assistance and support.

## **Options and choice for families**

The research has shown that kids and families are not a homogenous group and have varied lived experiences and goals. Working with them requires providing options and choices that fit the needs of all kids and families and reflect that circumstances can and do change over time.



# 09 Next Steps: Capacity Building Framework

## What will take place

The Capacity Building Phase of the Belonging Project will produce a Framework for Inclusion that will guide strengths and asset based community development activities with children and families in Tweed.

This report has captured the voices of children and families - what is important and contributes to a sense of belonging and connection, and the barriers that make this difficult. The report recommendations are a set of building blocks which should form the foundation of any engagement with children with additional needs and their families. The design of a Framework for Inclusion in Tweed will have these blocks as the foundations and the community will be asked to help build the framework and activities to be supported and the outcomes that will sit above.



A number of ideas have already come from this research project including a range of strategies families would like to see in Tweed to increase belonging and connection. They fall into several streams- from setting up new inclusive spaces and places for children, to advocating for change in existing services and mainstream settings. Also identified throughout the research are the existing strengths in the community - the resilience and innovation of families, the ongoing development of inclusive practise by service providers and initiatives taken by the broader community to make life better for kids. It is these skills and attributes that will be highlighted in the capacity building phase. Existing community networks will be expanded and built upon and in areas where improvements are needed, these examples of inclusive practice will be held up as what's possible.

## How will it take place

Community forums will take place with two groups across Tweed - children and families and community stakeholders.

The Family Day will build on the success of the Draw Listen Learn Day with Aboriginal Families and be held on a weekend at a local school with fun activities for kids and childcare provided.

Parents will have the opportunity to take part in workshops with the aim of developing innovative and creative solutions for increasing inclusion in Tweed. Families who have already taken part in the Belonging Project will be invited directly and the event promoted widely across the community for other interested families.

The workshop will be designed to capture the learning of the research report and existing knowledge and models of Asset Based Community Development while facilitating parents to refine and prioritise proposed activities. The Building Blocks for a Capacity Building Framework will be presented and input sought for other key influencing factors to be considered in its development.



The community stakeholder day will be a Change Workshop, with key players who work with children with disability and families in Tweed invited - across early childhood services, disability services, early intervention, community and allied health services. These stakeholders will be taken through the project and research to date, given the outcomes of the Building Blocks Family Day and asked to start a conversation about how they could be a part of the proposed activities.

While the aim of the family forum is to create ownership over the process by the community, the aim of the stakeholder forum will be to spark interest and 'buy in' from service providers. It will be an opportunity to look at the similar outcomes that services are looking for and creating networks to see these achieved collaboratively across the same community of families, in ways that will work for children.

The outcomes from both of these forums will provide the basis for producing a set of capacity building activities, situated within a framework developed in consultation with the community. The activities, framework and outcomes will guide the Belonging Project through to June 2014.

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