Research report

# Feeling safe, being safe:

What is important to children and young people with disability and high support needs about safety in institutional settings?

Sally Robinson

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February 2016

# About this report

## Project team

The Royal Commission into Institutional Responses to Child Sexual Abuse commissioned and funded this research project, undertaken by the Centre for Children and Young People at Southern Cross University (SCU).

The centre's interdisciplinary research covers a wide range of issues that impact children's and young people's rights and wellbeing. Projects and publications cluster broadly around one or more of the themes of rights and citizenship; health and wellbeing; learning and education; and environment.

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|---|---|---|
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The views and findings expressed in this report are those of the author(s) and do not necessarily reflect those of the Royal Commission.

## Acknowledgements

The project team would like to thank the children, young people and families who worked with us to share their perspectives on safety and harm. We are grateful to you for sharing your energy, expert knowledge and good humour so generously.

Thanks are also due to the people who supported us all in the project through assisting children and young people with good will, commitment and interest.

Sally Robinson wrote the final report. We greatly acknowledge Anne Graham's and Judy Cashmore's contributions to the literature review, and Lel D'aegher for collecting and analysing data.

## Report details

This document is the final report for the project titled '*Feeling safe, being safe: What is important to children and young people with disability and high support needs about safety in institutional settings?*'.

## Disclaimer

The views and findings in this report are those of the author(s) and do not necessarily reflect those of the Royal Commission. Any errors are the author's responsibility.

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# Feeling safe, being safe:

## What is important to children and young people with disability and high support needs about safety in institutional settings?

Sally Robinson

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# Executive summary

## Introduction

### The Royal Commission

In January 2013, the Honourable Dame Quentin Bryce, (then) Governor-General, appointed the Royal Commission to inquire into institutional responses to child sexual abuse.

The Royal Commission must recommend laws, policies, practices and systems that will effectively prevent or, where it occurs, respond to abuse. To ensure it provides authoritative, relevant recommendations, it has developed a detailed research program.

### This report

This report explores what helps children and young people with disability and high support needs to feel and be safe in institutional settings. The study addressed the following questions:

1. What does 'being safe' mean to children and young people with disability and high support needs?

2. What helps and hinders children and young people with disability and high support needs in feeling and being safe in institutional settings?

3. How do people who provide support perceive and respond to children's and young people's concerns about their own safety?

It is a small-scale study linked to a larger research project about children's and young people's views on safety, *Having a Say: Exploring issues of safety with children and young people*, undertaken by Australian Catholic University (ACU). The study was deemed necessary to ensure the inclusion of children and young people with disability who are unable to participate in research without specifically designed methods and additional research support. All of the children and young people who participated in this study had cognitive impairments, and many had multiple impairments.

## Methods

Twenty-two children and young people aged between 7 and 25 contributed to the study. The support needs of children and young people ranged across a broad spectrum. All participants had significant support needs that influenced the ways in which they lived their daily lives and their close and wider relationships, and played a significant role in the institutions with which they were in close contact.

To be as responsive as possible to the communication preferences and support needs of children and young people with disability, the project team developed and used a multi-method approach. Using a range of research methods, including photo elicitation, pictorial

mapping, storyboards, talking mats and walk-along interviews, researchers worked with each participant for between one and three interviews, individually and in small groups, to develop a view of their understanding and experience of personal safety in the institutions with which they engaged.

Individual and small group interviews were also conducted with six family members and 10 professionals. Professionals came from school, after-school care, vacation care, disability support, therapy, respite, advocacy and supported employment domains. A careful and considered ethical approach was taken to minimise the likelihood of the research causing any distress to children and young people or their families.

## Key findings

The gaps in the research emerging from a substantial literature review undertaken for the project underline that abuse research has paid little attention to the perspectives of children and young people with disability, to preventative and safeguarding approaches, or to factors that promote personal safety for children and young people with disability.

### What does 'being safe' mean to children and young people with disability and high support needs?

Children and young people provided a wealth of information about what 'being safe' meant to them, both in conversation with the researchers and through their pictorial maps. This included:

- feeling safe and secure
- being protected
- not being hurt
- not trusting strangers
- following rules – written and unwritten
- having strategies
- having some control of the situation.

Many children and young people used physical safety as a starting point in their conversations about safety, and moved from discussing keeping doors locked, staying off the road and so on to talking about relational safety.

Children and young people also pointed out in a number of ways that it can be very hard to know what is safe or unsafe, especially for children and young people with higher support needs. They talked about complexity in relationships, when people were trustworthy on some occasions but not others. Few remembered learning about safety, either at school or anywhere else.

Families and professionals all viewed the children's and young people's understanding of safety as limited. They shared concerns about how the ways in which service systems operate make it very difficult for children and young people with high support needs to identify trustworthy and untrustworthy people in their lives. They saw a lack of safety (self-

protection) skills in children and young people – in some cases feeling that these could not be learnt, and in others that they were developing slowly.

## What helps and hinders children and young people with disability and high support needs in feeling and being safe in institutional settings?

Children and young people described a series of factors that helped them to feel and be safe. These included having a secure foundational space (home, for most), having friends, feeling known and valued, having someone to confide in, avoiding contact with people they didn't know (both strangers and professionals who were little known), feeling able to tell someone if they felt unsafe, and having appropriate opportunities to learn about how to be safe (both formal and informal).

Things that made it difficult for children and young people to feel and be safe included fears about their safety, feeling out of control in situations, the impact of having experienced various forms of abuse, peer pressure, being under-supported through transitions and complexity in their family lives.

The institutions in which children and young people with disability frequently spend a high proportion of their time influence their findings. Young people in this research had weak affiliations with mainstream institutions, apart from school. Most children and young people in this study predominantly used services specifically for people with disability, and hence the findings in this research relate most centrally to these institutions.

## How do people who provide support perceive and respond to children's and young people's concerns about their own safety?

Families had a limited knowledge of the actions children and young people took to keep themselves safe, and mostly felt that their children did not, or could not, act to keep themselves safe. Professionals commented on a greater number of people, but did not know them as well. Shared views about the ways in which children and young people acted to keep themselves safe included using safety strategies and relying on established networks.

Families and professionals spoke about the actions they took to build a sense of safety with and for children and young people. Families emphasised the importance of providing a loving foundation, building networks and managing relationships with disability support staff. Professionals expressed the importance of developing safety skills with the young people with whom they worked. Both groups perceived a need to build capability and confidence, put support into place, focus on education and communication, and take action on behalf of the children and young people.

Families and professionals outlined ways in which they felt children and young people risked their personal safety. Families focused more strongly on the individual qualities inherent in their children's characters and impairments, while professionals emphasised their lack of knowledge, and risky social practices and relations. Families and professionals also described how they as supporters responded to these risks and potential harm – families by worrying, and both groups by focusing on prevention, managing risks and taking action.

Finally, both families and professionals commented on the limited degree to which they felt systems recognised children's and young people's perspectives of safety. This was because of the high number of staff members that children and young people do not know, the fact that their needs were poorly met in schools, and services' lack of focus on disability support needs and overly bureaucratic risk orientation.

## Main conclusions

A number of key issues important to children and young people, policy and practice can be drawn from the study findings. In each case, the critical issues children and young people and their supporters identified are consistent with the existing literature on abuse and safety for children and people with high support needs due to cognitive disability.

- **Systemic impacts on children's and young people's lives need to be addressed.** The effects of systemic limitations and failures, segregation, lack of choice and discrimination were evident in the research findings. Children and young people with cognitive disability had very different living patterns to their peers without disability. They were vulnerable due to the multiple ways in which institutional practices acted to isolate them from local communities and long-term support relationships.

- **Work is needed to assist children and young people and their supporters to recognise and assess the relative risk of harm.** This study's findings, together with related literature, indicate that while some children and young people with high support needs are unable to protect themselves against harm, many others have or can develop basic self-protection skills but find it very difficult to identify or understand more systemic risks or to avoid or respond to more insidious abuse. For example, several children and young people expressed a sense of personal responsibility for keeping themselves safe and did this by making themselves less visible to avoid attracting attention. This may help them avoid harassment, but it also increases the risk of predatory abuse. A risk management focus may act to 'put a lid' on concerns around safety and harm, rather than create relational solutions for children and young people who require sustained involvement with trusted adults to feel and be safe and to express this. In most cases, the emphasis that children and young people and their supporters placed on 'stranger danger' did not take into account the difficulty of calculating risk when meeting new people or acknowledge that a high proportion of children and young people with cognitive disability are abused by people they already know. While several children and young people talked about times when it was clear that they, or situations around them, were not safe (such as being physically injured or bullied), it was much more difficult for them to articulate uncertainty or disquiet, particularly about people in authority. The implications of this are twofold:

  o Many children and young people lack the skills and support to identify and act on feelings and instincts that could keep them safer from potential abuse in institutional settings.

  o A diminution of the social life of children and young people as they grow and develop, as a number indicated that they generally feared people they did not know (for example, people standing at the bus stop).

- **The nature and quality of support relationships need to be monitored in a strategic and concerted way.** Children and young people and their supporters placed a high priority on relational support to protect them against harm across multiple institutional settings. This is required at individual and systemic levels, because relationships feature centrally in current and forthcoming large-scale policy developments. In the future, care – which is currently service-oriented – will be provided in much more devolved and individualised environments, increasing the importance of identifying supportive practice and intervening in problematic relationships. One of the biggest risks is the high number of strangers or new people in the lives of children and young people with disability, and the tensions that arise between needing to trust people who are there to support them and the risk this poses. This study (and others) showed that the reliance children and young people have to place on relationships with staff members at an individual level is a source of tension and concern, due to their lack of knowledge and education about abuse and their limited capacity to act on concerns. At a systemic level, high staff turnover, the lack of training and skill in workers and managers, and increased trends towards casual staffing all increase risk.

- **Evidence-based educational resources and strategies are needed to improve children's and young people's capacity to identify and respond to potential harm.** Such resources also need to include initiatives for professionals and families, to ensure children and young people are effectively supported if they disclose harm, and that harm is recognised and responded to if they provide indications through behaviour or other indirect means. This will support efforts to decrease the high rates of harm; increase the skills of children and young people and their supporters; and help children and young people identify and act on feelings and instincts, which could keep them safer from potential abuse in institutional settings.

- **Active participation of children and young people with disability needs to be supported so they are better involved in decisions across in a number of domains, including their education, health and disability support services.** The diversity of children and young people with significant support needs who participated in this study demonstrates that it is possible to have safe, creative conversations about sensitive topics in their lives. More than a matter of good practice, this is also a requirement under the United Nations' Convention on the Rights of the Child and Convention on the Rights of Persons with Disabilities. Tailored, innovative methods for effectively listening and responding to the diverse views and perspectives of children and young people with cognitive disability need to be encouraged, to ensure they can contribute to their personal circumstances, service environments and broader policy change.

There are marked similarities between the findings of this study and the ACU's *Having a Say* study, including the importance of having reliable, safe and trusted adults in children's and young people's lives, and the foundational nature of home in building resilience and confidence. Where differences are evident between the two studies, they are important because they are generally linked to systemic disadvantage. Differences included the way in which some children and young people with disability equated feeling safe with being safe; additional barriers to being able to implement safety strategies; responses to feeling intimidated and threatened; and a more frequent lived experience of abuse.

# Part 1:
# Context and conclusions

# 1 Context and conclusions

## 1.1 Introduction

> **Key points**
>
> This Royal Commission seeks to provide a broad-ranging, national response to survivors of child sexual abuse in Australian institutions. It is learning about their experiences through private sessions and public hearings. It also has an extensive research program, which this report falls under, to help the Commissioners identify practical, relevant and evidence-based recommendations for change.
>
> This report explores factors that help children and young people with disability and high support needs to feel and be safe in institutional settings.
>
> It is a small-scale study that both stands alone and informs a larger research project about children's and young people's views on safety. The study was identified as necessary to ensure the inclusion of children and young people with disability who are unable to participate in research without specifically designed methods and additional research support. All of the children and young people who participated in this study had cognitive impairments, and some also had multiple impairments.

### The Royal Commission

#### Inquiry reflects the community's call for action on abuse

When a child is sexually abused while in the care of an institution, the impact can be devastating and last for a lifetime. It can leave a traumatic legacy for the victim's family and for future generations.

Although there have been some inquiries with limited terms of reference, in recent years it became clear to the Australian community that a broad-ranging, national response was needed. In January 2013, the Honourable Dame Quentin Bryce, (then) Governor-General, appointed the Royal Commission to inquire into institutional responses to child sexual abuse.

#### Private sessions, public hearings and research all give insights

The Letters Patent give the Royal Commission comprehensive terms of reference. Through private sessions and public hearings it bears witness to the trauma inflicted on children who suffered sexual abuse in an institutional context. It must also focus on systemic issues.

At the end of the inquiry, the Royal Commission's final report must identify best practices and recommend laws, policies, practices and systems that will effectively prevent or, where it occurs, respond to the sexual abuse of children in institutions.

The Royal Commission is approaching this task in three ways:

| Private sessions | These sessions enable survivors to speak directly with a Commissioner about their experiences in a private and supportive setting. |
|---|---|
| Public hearings | Public hearings are a formal process during which the Royal Commission receives evidence following investigation, research and preparation. |
| Research and policy | The extensive research program includes research reports, roundtables and issues papers. |

## The extensive research program will support the final recommendations

To ensure the Royal Commission provides authoritative, relevant recommendations to the government, institutions and regulators, it has developed a detailed research program. The program focuses on eight themes:

1. Why does child sexual abuse occur in institutions?
2. How can child sexual abuse in institutions be prevented?
3. How can child sexual abuse be better identified?
4. How should institutions respond where child sexual abuse has occurred?
5. How should government and statutory authorities respond?
6. What are the treatment and support needs of victims/survivors and their families?
7. What is the history of particular institutions of interest?
8. How do we ensure the Royal Commission has a positive impact?

The research program helps the Royal Commission to:
- obtain relevant background information
- fill key evidence gaps
- explore what is known and what works
- develop recommendations that are informed by evidence, can be implemented and respond to contemporary issues.

For more on this program, please visit www.childabuseroyalcommission.gov.au/research.

## This report

*Feeling Safe, Being Safe* explored what helps children and young people with disability and high support needs to feel and be safe in institutional settings. It is a small-scale study linked to the ACU's larger *Having a Say* study, which uses a mixed methods design to collect data from a broad range of children within a diversity of institutional contexts and locations across Australia. The *Feeling Safe, Being Safe* study was identified as necessary to ensure the inclusion of children and young people with disability who are unable to participate in research without specifically designed methods and additional research support.

All of the children and young people who participated in this study had cognitive impairments, and some also had multiple impairments. They are referred to in this report as 'children and young people with disability and high support needs', or as 'children and

young people with cognitive disability'. This work does not claim to represent issues for all children and young people with disability or all children and young people with high support needs.

To fulfil its aim of exploring what helps children and young people with disability and high support needs to feel and be safe, the study addressed the following questions:

1. What does 'being safe' mean to children and young people with disability and high support needs?

2. What helps and hinders children and young people with disability and high support needs in feeling and being safe in institutional settings?

3. How do people who provide support perceive and respond to children's and young people's concerns about their own safety?

The support needs of the participants in this study are such that it is not possible to directly ask the same research questions as the ACU *Having a Say* study. However, the results have been analysed to allow comparison with the ACU study's findings, particularly with respect to:

- how children and young people with disability and high support needs conceptualise safety

- how they perceive safety in institutions

- their views on why they feel this way

- what they think is done to respond to safety issues and risks in institutions

- what they think should be done to respond to safety issues and risks.

# 1.2  Methods

**Key points**

- Twenty-two children and young people aged between 7 and 25 contributed to the study.
- All of these children and young people had cognitive impairments, and many had multiple impairments.
- The children's and young people's support needs ranged across a broad spectrum. All participants had significant support needs that influenced how they lived their daily lives and their close and wider relationships, and played a significant role in the institutions with which they were in close contact.
- A multi-method approach was developed and used, to be as responsive as possible to the children's and young people's communication preferences and support needs.
- Using a range of research methods – including photo elicitation, pictorial mapping, storyboards, talking mats and walk-along interviews – researchers worked with each participant for between one and three interviews, individually and in small groups, to develop a view of their understanding and experience of safety in the institutions with which they engage.
- Individual and small group interviews were also conducted with six family members and 10 professionals working across a number of institutional environments.
- A careful and considered ethical approach was taken to minimise the likelihood of the research causing any distress to children and young people and their families.

Qualitative research was carried out with children and young people with cognitive disability, their families and professionals working to support children and young people in a range of domains. The research was conducted in south-east Queensland and north-east New South Wales in a range of large and small regional centres and in rural communities. In order to protect participants' privacy, the report provides no further geographic detail. Ethical approval to conduct the study was obtained through ACU's and SCU's human research ethics committees.

## Participants

Twenty-two children and young people contributed to the study. Children and young people were aged between 7 and 25 (figure 1). Young people aged between 18 and 25 reflected on their experience of using children's institutions. Gender was evenly split, with 11 boys and young men, and 11 girls and young women participating.

Children and young people who took part were connected to special and mainstream schools (mostly in special units), disability support services, respite services, out-of-home care (OOHC), specialist disability vacation care services, therapy services (psychology, speech and physiotherapy), employment support services and community centres.
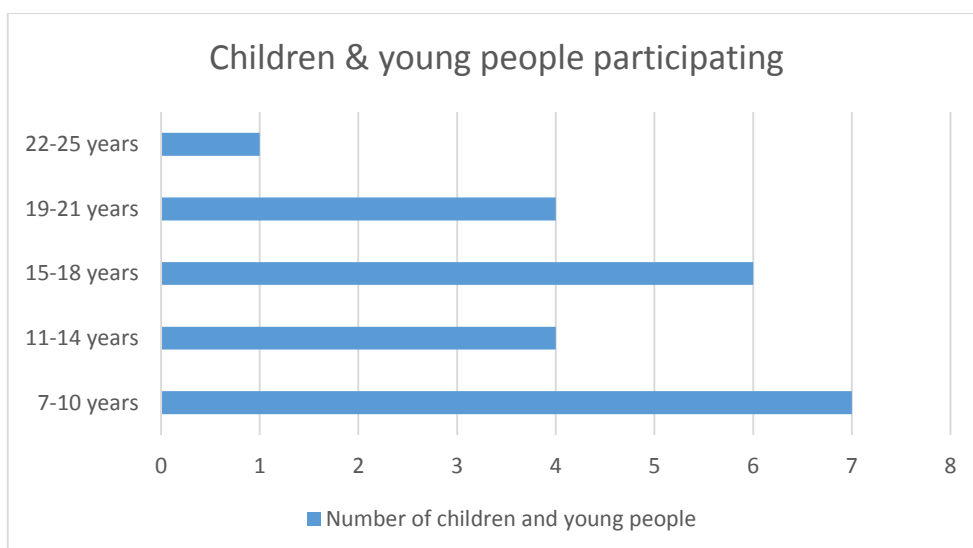
Figure 1: Children and young people participating in the research

The children's and young people's support needs ranged across a broad spectrum. This research drew from the interactional understanding of disability (Shakespeare, 2014), which understands the experience of disability as a holistic one where the effect of impairment is acknowledged along with social and systemic factors, which together encompass the experience of disability. As such, children and young people and their families were not asked for information about disability type. They were, however, recruited to the study on the basis that they had lived experience of cognitive disability and high support needs. It was clear in working with the children and young people that all participants had significant support needs that influenced how they lived their daily lives and their close and wider relationships, and played a significant role in the institutions with which they were in close contact. For example, all participants used specialist disability support services. A significant proportion used therapy services of various forms, and three used augmentative communication and had limited or no speech. Six were primarily reliant on other people for physical mobility.

It is important to note that more than half of the children and young people in this study disclosed having previously experienced harm in institutional contexts, including bullying, peer-to-peer abuse and violence, sexual harassment and sexual assault, and victimisation because of their impairment. Because the research focused on safety, and for ethical reasons, the research team did not seek details about this harm. However, this is a high proportion and is consistent with previous research on the abuse and victimisation of people with disability (see section 2.1).

After making appropriate checks, the research team were assured that none of these disclosures of abuse, bullying or victimisation pertained to a current or recent experience; all were historical, had been previously disclosed and had been reported to the appropriate authorities. The research team were not required to make any reports of abuse, bullying or victimisation to authorities. Please refer to Appendix B for details about the ways in which the research team worked to ensure the safety of children and young people who disclosed harm in the research.

Informal discussions and meetings were held with service providers and family members regarding all children and young people during the recruitment and planning phase of the research. Formal interviews were conducted with a subset of 16 people in this group, comprising six family members (five mothers and one grandmother) and 10 professionals. Professionals predominantly worked in the disability support sector, reflective of the institutional spaces in which the children and young people spent their time. They represented special school, vacation care, disability support, speech therapy, respite, advocacy and supported employment domains.

The research team conducted significantly fewer interviews with family members and workers than originally estimated. The study design included interviews with at least one adult connected to each young person, and preferably two from separate domains (for example, home and school). For eight children and young people, we were able to interview either family members or professionals who knew them well. In four cases, we were able to formally interview two sets of supporters from the family and professional support domains. Ten children and young people participated with family consent but no involvement from their family members. Staff members expressed the view that these families held a general level of trust in the service's operations, and normally consented to all activities to which their child was invited at the service.

Recruitment for this study was difficult compared to research this team has conducted using similar methods but on less sensitive topics. An extensive recruitment effort was made through promoting the study via disability support services, advocacy and information services, child and family services, schools and other public opportunities (for example, at inter-agency meetings of community workers, and seminars). Broadcasting through newsletters and information on websites was unsuccessful. Direct contact with mainstream schools and mainstream holiday care services did not result in any participants. Most participants were recruited through direct contact with well-placed workers in services, who in turn made personal contact with the families of children and young people, and in a small number of cases, directly with young people.

## How children and young people were involved

A combination of methods was used, including individual and small group interviews, and customised, individual approaches for children with very high support needs, as shown in Figure 2. Working on the basis of 'whatever it takes' for children and young people with cognitive disability to be able to participate and share their views, we used participant observation strategies in the early stages of the research to build a comfortable relationship, and consulted with the people who support them to tailor methods and resources that work most effectively for each individual. This multi-method approach was developed and used to be as responsive as possible to the children's and young people's communication preferences and support needs.

Some families of children and young people with very high support needs collaborated with the researchers to try to find creative ways of involving them. For example, as part of the

research, one family investigated the possibility of incorporating a module about safety into their child's communication program, in the hopes that together with his speech therapist, he might learn a new method for sharing feelings about being safe or unsafe with his family. Unfortunately, this proved to be too complex a task in the short term.
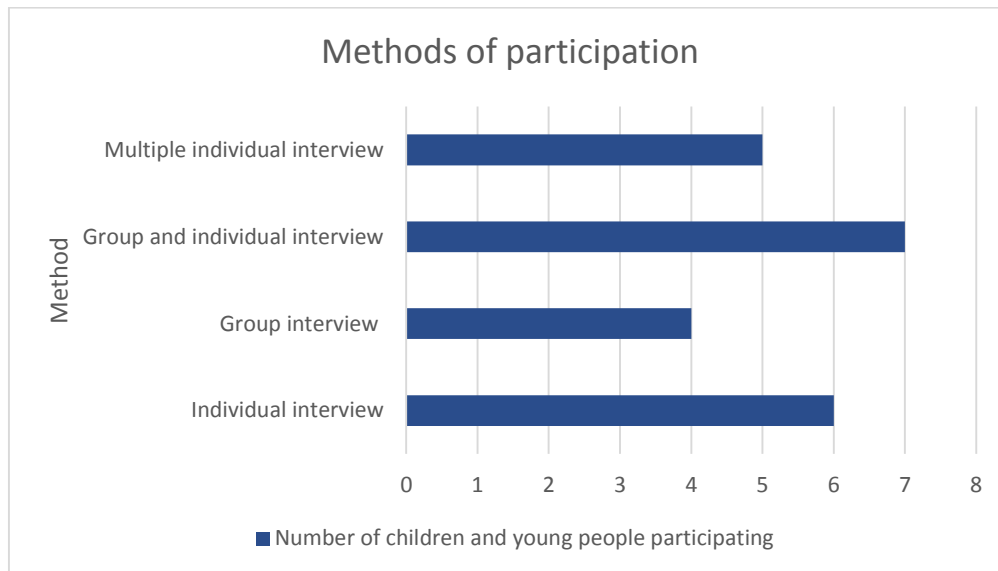


Figure 2: Methods of participation

## Individual contributions

Using a range of research methods – including photo documentation, photo elicitation, pictorial mapping, storyboards, talking mats and walk-along interviews – researchers worked with each participant for between one and three interviews to develop a view of their understanding and experience of personal safety in the institutions with which they engage (Boxall & Ralph, 2009; Murray, 2004; Notara & Robinson, 2013; Robinson, 2014a; Sloper & Beresford, 2014).

Interviews were conducted using a range of tools (for example, games and other stimulus materials such as squishy balls, toys and drawing materials) to minimise the formality of the experience and help ensure the children and young people felt comfortable.

The five children and young people who participated in multiple individual interviews all had significant support needs. Repeat visits allowed the research team to build rapport, extend the depth and quality of data we could collect, and use multiple methods.

This approach was customised for each child and young person; focused on understanding and documenting their lived experience of safety in the context of at least one major institution; and involved young people and trusted supporters across multi-institutional and private domains, and also independently.

A 'tool kit' of methods was developed and used by the researchers, and included:

*An information resource:* An easy-read and pictorial resource assisted in providing the children and young people with a wider understanding of the dimensions of personal safety when their understanding of the concepts was limited. It covered feeling safe in your body, in different places, with different people and in your feelings, and how you might feel if you don't feel safe. It also provided a simple safety plan outlining who you can go to for help if you feel unsafe. This resource was distributed to participants. Many young people were keen to take this home with them after the interviews.

*Game-based activities:* Some of the child-friendly methods used in two large studies children's wellbeing (Graham et al., 2014; Skattebol et al., 2013) have been used successfully with children with disability to talk about relational issues, and the research team adapted them for the safety arena. These included games in which small group participants chose an object that reminded them of something (or someone) that helps them feel safe and talked about their choice; scenario-based games; and activities ranking the comparative safety of different domains.

*Pictorial mapping:* Pictorial mapping was completed with most participants as a research activity. Mapping helped the research team work with the children and young people to identify the places, people and relationships that created a sense of personal security for them.

*Photographic methods:* Some children and young people participated in photo documentation, and photo elicitation was used with a small number of them. Working with supporters, researchers identified places and people likely to be important to individual children and young people (for example, a school playground) and either took photographs of these or used photographs of similar places. In interviews, the research team then used a guided process to elicit responses from the children and young people about how these places and people either facilitate or constrain safety (Dennis et al, 2009).

*Guided collage:* Some children and young people used picture-based collage, using drawing, collage and pre-prepared images that supporters had identified as likely to resonate with their lived experience of safety and concerns about safety.

*Communication tools:* Specialist communication tools such as storyboards, Talking Mats and Mayer Johnson Boardmaker pictogram signs were used to facilitate communication with children and young people who communicate primarily without speech.

*Walk-along interviews:* For children and young people who prefer not to sit still, or who dislike formal processes, the research team used walk-along (or go-along) interviews. These involved fieldworkers accompanying children and young people in their activities (for example, playing in the backyard or doing an activity at holiday care) and engaging in more informal conversation about the research topics.

## Small group contributions

In addition to the abovementioned individual interviews, small groups of up to four children and young people were engaged using the same methods to explore their understandings of safety. Following group activities, most group members also participated in an individual

interview, where they used pictorial mapping and game-based activities, as detailed in Appendix C, to describe the safe places and people in their lives to the researchers.
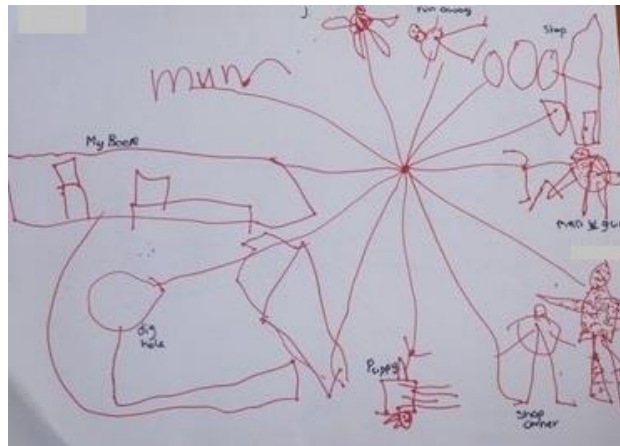


Eric's map, aged 9

Seven children and young people participated at first through small group activities and then extended their involvement through pictorial mapping and individual conversations. This structured approach was helpful for these young people. Four children chose to only participate in group activities and declined to continue with individual activities, at least in part due to concurrent activities being offered by their support service that they found more appealing. Of the six who participated in a single interview, all but one were quite articulate and able to express their views clearly using the adapted methods. Consequently, they did not feel the need for further engagement after one interview.

## How people who supported children were involved

Informal meetings and interviews were conducted with at least one person who supported each child or young person in different parts of their lives (for example, at school and home). The focus of the informal meetings was to learn how best to work with the child, to tailor research resources, to observe support relationships and to observe the institutional setting. Interviews focused on these supporters' perspectives on how the child or young person understood safety, how their safety was mediated by others, and the ways in which they felt that children and young people perceive and respond to safety and lack of safety in their institutional environments.

Interviews were conversational and focused on the following areas:

- How are you connected to [young person]?

- Can you tell me about the ways that you think they understand safety?

- Do you see [young person] act to keep themselves safe? How?

- What do you do to support this?

- What do they do if they feel unsafe?

- What action do you take in response to this?

- Do you see [young person] risk their personal safety? How?

- What action do you take in response to this?

- Do you think the [relevant system] acknowledges children's and young people's perspectives of safety? Why/why not?

- Is there anything else you would like to discuss that I have not raised?

## Data analysis

Interviews were digitally recorded with the consent of the children and young people (and their parents or guardians) and later transcribed. Visual materials (for example, maps) were photographed, and the children and young people were given the option to keep any material they had created. The children's and young people's photos and artwork were downloaded and securely stored, along with their captions.

All data from interviews and the photographic and mapping material were manually coded for concepts commonly expressed across the data. These codes were grouped or categorised into themes according to the knowledge emerging about key concepts. Analysing these themes created new categories of ideas about safety, which were tested by exploring how certain themes intersected and how multiple themes interacted. For example, the category of 'relational support' emerged from a combination of the themes of having a 'go to' person, feeling known and valued, and telling someone. These categories were catalogued and used as the foundation for our findings (Richards, 2009; Blaikie, 2000).

## Key ethical considerations

Ethical approval for the research was obtained through ACU (as this study was embedded in a wider study of children's safety), SCU and the Queensland Department of Education and Training. Ethical approval was also sought through the NSW Department of Education, but lengthy administrative delays precluded participants being directly recruited and interviewed within the school setting in New South Wales (although the study design had assumed only incidental recruitment via schools). In addition to compliance with ethics protocols, the research team used a very careful and considered approach to minimise the likelihood of the research causing any distress to the children and young people and their families. No children or young people withdrew during the research. The research team followed up on concerns that arose during interviews with two participants relating to their emotional wellbeing, but these were not directly caused by their involvement in the research. A free counselling service was available to participants but not taken up by anyone.

All names used in this report are pseudonyms.

Those children and families who chose to use photographic methods participated in additional conversations around consent and the potential use of photographs in the research. Material that appears in this report has the consent of both the children and

young people and their parents, and is cropped to minimise the identification of individual participants.

# Part 2:
# Findings

# 2 Findings

## 2.1 Literature review

**Key points**

- The gaps in the research emerging from this review underline that abuse research has paid little attention to the perspectives of children and young people with disability; to preventative and safeguarding approaches; or to factors that promote personal safety for children with disability.
- Research on the ethics and practice of including children and young people with disability in research on sensitive issues shows the importance of both promoting the ethical dimensions of participation and mitigating perceived silencing or minimisation of abuse and neglect.
- There is limited research where children and young people with disability talk about sexual abuse. Existing research shows that some children and young people accept peer abuse as normal behaviour, have unrealistic ideas about how to escape unsafe situations, and lack a sense of privacy or bodily integrity due to high levels of medical or personal care. Some research discusses the importance of mutuality and reciprocity in relationships to children and young people, having a sense of agency and being respected.
- Evidence about abuse prevention shows that the risk of maltreatment is reduced for children and young people with disability when their dignity and humanity is respected and they are treated as equal citizens, and as valued and included community members. These approaches to safeguarding focus on developing relationships, reducing social and physical isolation, and building strong and ongoing formal and informal networks for children and their families across multiple areas of their lives.
- In stark contrast, relevant research shows that a series of factors negatively impact the likelihood of children and young people receiving effective and timely support if they experience abuse. This includes a reluctance among professionals to believe the high rates of abuse children and young people experience, disbelief of their accounts and a lack of skill in providing appropriate support.
- The literature addresses the need for training and education for children and young people and those who support them. A range of responses have been identified as necessary to overcome families' reluctance to address sexuality and teachers' embarrassment, and the need for professional development in disability support services alongside capacity-building strategies to help children and young people better recognise and respond to the threat and experience of harm.
- The research reported above intersects with a national policy environment in which the rights and needs of children with disability are not well considered outside of the disability policy arena.

Evidence increasingly points to the importance of accessing children's and young people's views and perspectives to help ensure policies and programs respond to their needs and lived experience, and cohere with national and international human rights obligations. Frequently overlooked in research and consultation, the high rates of harm that children and young people with disability experience means their participation is all the more important (Stalker & McArthur, 2012).

The research team conducted a literature review to inform the *Feeling Safe, Being Safe* research project. The key themes emerging from this review informed the project methodology and this final report, providing a base and context for the qualitative research results.

The review of existing research was structured around four key areas:

- the ethics and practice of including children and young people with disability in research on sensitive issues

- sexual abuse and abuse of children and young people with disability

- the perspectives of children and young people with disability about sexual abuse

- promoting personal safety – safeguards and abuse prevention.

## Review methodology

To conduct the review, the research team located published peer-reviewed academic literature and well-referenced grey literature (for example, government reports and significant non-government research reports) by searching multiple databases and drawing on their existing knowledge of previous research. The search drew from a variety of databases, including EBSCO: Education Research Complete; ERIC; Psych*; Health Source*; Google Scholar; ProQuest Social Science Journals; Psychology & Behavioral Sciences Collection; and Sociological Abstracts. Search strategies involved combinations of various terms, including disability, children, young people, safety, abuse, research, participation and ethics.

One hundred and seventy-nine sources were located, primarily articles in peer-reviewed journals. One hundred and thirty-six sources analysed the experience and impact of all forms of abuse (generally spanning physical, sexual and emotional abuse and neglect) on children and people (more generally) with disability. Within this, 33 academic articles focused specifically on describing and analysing the sexual abuse of children with disability. Only four of these included the perspectives of children and young people. Sixteen articles and academic books made reference to this specific body of research and also wider sociological theory to develop guidance about preventing harm and promoting personal safety for children and young people with disability. The research team also identified and used 15 research reports from government and non-government sources that directly addressed or included the abuse and neglect of children with disability. Finally, the research team located 27 articles on methodology and ethics in research with young people with disability. Very little of this research includes the perspectives of children or young people with disability.

## The ethics and practice of including children and young people with disability in research on sensitive issues

The involvement of children and young people with disability in research is increasing, albeit slowly and from a very low base. Their contribution to research is still far from being taken for granted, and their perspectives are mainly sought in research that is specifically targeted at children with disability, rather than included in wider research about child abuse and neglect. It is difficult to locate research that includes children with disability as a group within wider research on topics of importance to all children, including in relation to safety and harm (Foley et al., 2012; Goodley & Runswick-Cole, 2011; Skattebol et al., 2013).

There are good reasons for directly involving children and young people with disability in research concerning their lives (Briggs & Hawkins, 2005; Skattebol et al., 2013; Sloper & Beresford, 2014). First, it is important to help ensure policies and programs are responsive to children's needs and lived experiences. A number of studies have shown that children with disability and their parents have varying perspectives on how the experience of impairment and disability affects children's lives (Goodley & Runswick-Cole, 2011; Sloper & Beresford, 2014; Stalker & Connors, 2005). This includes their concerns and worries, stresses, emotional wellbeing, goals and aspirations. Such evidence points strongly to the need for research that works directly with children with disability, and indicates that while the additional perspectives of parents and other supporters are valuable, they cannot substitute for children's perspectives in ensuring policy, programs and practice are well targeted and effective.

Second, documenting the views and experiences of children and young people with disability helps to mitigate the perceived silencing or minimisation of abuse and neglect amid other competing domestic and institutional pressures. The experience of abuse and neglect is sometimes minimised and downplayed when other competing pressures within families or organisational management structures are prioritised, when children have challenging behaviour, or when they have non-standard communication or little or no language to describe harms (Foley et al., 2012; Murphy et al., 2007; Robinson & Chenoweth, 2011; Sobsey & Mansell, 1994). The high rates of harm that children and young people with disability experience makes their participation all the more important (Briggs & Hawkins, 2005; Mepham, 2010; Murray, 2004; Stalker & McArthur, 2012).

Research with children and young people with complex healthcare needs about involvement with multiple agencies has highlighted how family members are often needed to help with their communication and to advise on the best ways for researchers to try to communicate with them (Watson, Abbott & Townsley, 2007). This study also noted the number of barriers to commencing the research, such as guardians telling them that a child would not be able to take part. To overcome this barrier, they first interviewed parents and explained the research process with children as part of the interview. Lewis and Porter (2004), in their guidelines for interviewing children and young people with disability, caution against over-formalising the process of hearing the views of children with disability, particularly those with cognitive disability.

Third, a number of ethical dimensions need to be considered when including children and young people with disability in research. Excluding children with particular forms of

impairment simply because it would make it more difficult to conduct the research is not ethical. Sloper and Beresford, leading UK proponents of research with children with disability, note that it is most often older, less severely disabled and more articulate children who participate in research (2014). They call for the use of methods to include children with limited or no speech and cognitive impairments, and for approaches that engage children with disability throughout the research process (see also Fisher & Robinson, 2010). Boxall and Ralph (2010) point out the benefits for people with high and complex support needs of research that is designed to match their interests, and note the importance of identifying the benefits to both individuals and those who gain new appreciation and respect for the capability of the participants (such as staff members or families).

There are now well-documented ethics and principles to guide safe, respectful research with children and young people, all of which pertain to those with disability. Recent work by Graham, Powell, Taylor, Anderson and Fitzgerald (2013) points to the integral role of reflexivity, rights and relationships in helping to develop the kind of ethical 'mindfulness' required throughout the research process to identify and attend to dilemmas and challenges that arise well after ethical review and approval. Likewise, Swain, Heyman and Gillman's (1998) nuanced consideration of research about abuse with people with intellectual disability highlights that ethics is a continuous process of decision-making. They discuss the need to carefully manage research relationships and acknowledge that the poverty of social relationships in some people's lives can lead to reliance on the research relationship.

Aligned in part to the UN Convention on the Rights of the Child (1990) and informed by the interdisciplinary fields of childhood and disability studies (Tisdall, 2012, Hill, 2006; Goodley & Runswick-Cole, 2011), key principles of ethical research emphasise the importance of:

- viewing children and young people with disability as persons in their own right and as worthy of recognition, respect and voice in research

- assuming young people's involvement in research takes place with the active support of people around them who will provide appropriate assistance and guidance if needed

- focusing on understanding and improving young people's lives and circumstances

- engaging critically with the ethical principles of respect, benefit and justice

- promoting communication and reflection in attending to the complex ethical issues that may arise in research of this nature (Graham et al., 2013).

## Wider evidence about abuse and sexual abuse of children and young people with disability

This review included a focus on the prevalence of harm to complement the very limited research based on the perspectives of children and young people themselves. Given the dearth of evidence on sexual abuse, it is augmented by research on the abuse of children with disability more broadly. In the interests of informing the wider research project, which seeks to discover children's and young people's perspectives on safety and harm, this section focuses on research about the prevalence of abuse among children and young people with disability in institutional environments.

As with much other disability research, this area is characterised by two kinds of research. The first is empirical studies, which use differing methodologies (often small-scale and/or qualitative) to describe different kinds of harm. Such research provides important insights into the experiences of abuse. It results, however, in widely variable and at times unreliable use of limited evidence, a lack of comparability between studies, and an unclear picture of the harm children and young people experience. There is little baseline evidence to provide a clear understanding of the scale of abuse (more generally) or the prevalence of sexual abuse (more specifically) in the lives of children and young people with a range of disabilities. The second type of research includes reviews and meta-analyses of these empirical studies, which apply critical analysis with the aim of effecting change. A number of strong reviews bring analytical strength and coherence to the body of empirical studies (Baladerian, 1991; Bruder & Kroese, 2005; Horner-Johnson & Drum, 2006; Stalker & McArthur, 2012). The research team has drawn on that work, in particular, in this review.

## Prevalence of abuse

Two review studies offer a robust discussion of the range and scope of research that estimates rates of abuse and neglect. Stalker and McArthur's review of recent research (2012) and Horner-Johnson and Drum's (2006) review of prevalence studies found that – while much research provided valuable insights on the experience of violence, exploitation, abuse and neglect for particular groups of people with disability – most of the research conducted between 1995 and 2012 is based on small or convenience samples and does not form a reliable basis for estimating prevalence. While it can indicate a problem of significance, prevalence may not be the most helpful indicator for informing policy and practice change. This is due to both the lack of reliable figures and the fact that it does not demonstrate the range of abuse; the impact of abuse and neglect in the lives of children and young people; or differentiation in the impact on children and young people according to social disadvantage, gender, culture, Aboriginality or other measures (Cashmore, Scott & Calvert, 2008).

Research about abuse more generally suggests that children and young people with disability experience abuse at considerably higher rates than their non-disabled peers. Two studies that are consistently regarded as reliable in estimating the prevalence of abuse found the risk of abuse for children with disability to be approximately 3.5 times higher than for children without disability in both the USA and World Health Organization (WHO) European countries — no Australian figures are available (Jones et al., 2012; Sullivan & Knutson, 2000). Sullivan and Knutson point out that the vast majority of children experienced more than one kind of maltreatment, with most experiencing neglect, followed by physical, emotional and sexual abuse. As Jones et al. noted:

> The results suggest that up to a quarter of children with disabilities will experience violence within their lifetimes and confirm that children with disabilities are three to four times more likely to be victims of violence than are their peers without disabilities (2012, p. 8).

For children with intellectual disability, communication impairments, behavioural difficulties and sensory disability, a range of studies show even higher rates of abuse (Brownlie et al.,

2007; Stalker & McArthur, 2012). Since abuse is likely to be under-reported, these figures may be even higher (UNICEF, 2005). As well as high rates of abuse, there is evidence that children with disability are often abused on multiple occasions (Kvam, 2000), and that the impact of this abuse is significant (Sequeira & Hollins, 2003).

There is a limited evidence base specifically about the sexual abuse of children and young people with disability. The prevalence studies referred to above note prevalence rates of 13.7 per cent for sexual violence, and risk estimates of 2.88 (Jones et al., 2012) and 3.14 (Sullivan and Knutson, 2000) – that is, children with disability are around three times more likely to experience sexual violence than their non-disabled peers.

### Recent research on the incidence of sexual abuse among children and young people with disability

The research team located seven empirical studies that have findings of particular relevance for this project. This research is from countries with systems and cultures comparable to Australia – the USA, Israel and New Zealand. No research of this nature has been conducted in Australia, an important gap in our knowledge.

A recent nationwide study of the experience of sexual violence among school students with disability in the US (Caldas & Bensy, 2014) reported on the experiences of 352 students, based on the reports from the students (15 per cent) or their families and advocates (85 per cent). Using a broad definition of sexual maltreatment (including contact and non-contact forms of harm), the researchers found that 75 per cent of young people who experienced sexual maltreatment reported 'severe' harm (contact forms of sexual abuse and assault), and harm occurred on more than 10 occasions to over 30 per cent of these children and young people. 'In over half of the incidences, the maltreatment reportedly occurred in classrooms or school common areas, which should have been under the direct supervision of school personnel' (p. 362). In just over half of the incidents, the perpetrator was an adult at the school; in other cases, the perpetrators were fellow students. In almost 25 per cent of cases, the school reportedly did nothing in response to allegations of assault or abuse. In keeping with other research, just over half of the sample who experienced child sexual abuse were boys (Briggs & Hawkins, 2005; Kvam, 2003; Sullivan & Knutson, 2000). This is considerably higher than comparable studies of people without disability, where far fewer men and boys report abuse (Caldas & Bensy, 2014). While the authors did not provide details about retrospective reporting timeframes, it is clear that students and their families and advocates were reporting on recent harm, not long-term historical abuse. In another study, teenage girls in the US with physical disability or long-term health problems reported forced sexual intercourse at twice the rate of girls without disability – 19.6 per cent versus 9.4 per cent (Alriksson-Schmidt, Armour & Thibadeau, 2010).

Several studies show that young people with disability who reported high rates of sexual abuse had other social risk factors that increased the risk of sexual abuse, such as taking illicit drugs, being involved in bullying, or being from an immigrant or low socio-economic community (Brunnberg, Bostrom & Berglund, 2012; Stalker & McArthur, 2012). Significant levels of violence at home and school, vulnerability to drug use, psychological bullying,

pornography and sexual abuse were found among 116 girls and boys with learning disabilities aged between 11 and 17 in New Zealand (Briggs & Hawkins, 2005). While school counsellors indicated that sexual abuse was substantiated for 44 per cent of girls in the study, 32 per cent of girls spoke with the researchers about their experiences. Sexual abuse was equally common for boys and girls. Older youths were responsible for sex offences in 54 per cent of cases; the other offenders were family and friends, primarily father figures. Just over one in five children (22 per cent) reported that other students at school had used either 'tricks' or force to involve them in underage sex. Just less than two-thirds of young people reported the abuse, with mixed results.

Grossman and Lundy (2008) compared data from sexual assault services providing support to children and adults reporting sexual assault, both with and without disability, in a US state. Women and girls were predominant in both groups, and around one-third were under 18 at the time of the sexual assault. There were more men and boys with disability than without. While the proportion who reported assault by professionals was quite small in comparison to assault by men known to them, children and adults with disability reported more than twice as many offences against them by professionals as did those without disability (2.9 per cent versus 1.3 per cent). The relatively low rates of attendance by people with disability at sexual assault support services (compared to people without disability) led the authors to suggest that there is a heightened risk of assault outside their family home, and that particular barriers prevent people with disability from accessing sexual assault support services.

An analysis of specialist police interviews in Israel with more than 40,000 children with disability reporting sexual abuse over a seven-year period revealed some concerning trends (Hershkowitz et al., 2007). Children with disability were significantly more likely than their non-disabled peers to delay disclosure or fail to report abuse when questioned. Children with higher support needs were found to be at greater risk of sexual assault, and to experience more severe levels of harm and associated physical injury. Abuse by non-parental figures was more common for children with disability than for their non-disabled peers (9 per cent), and highest for children with high support needs (15 per cent).

Together, these studies provide a concerning picture of:

- the high rates of sexual harm experienced by children and young people with disability compared to children without disability, across a spectrum of severity of abuse (Jones et al., 2012)

- abuse experienced in environments where children should expect supervision and support from teachers (Caldas & Bensy, 2014)

- multiple social risk factors in young people's lives that further increased the risk of sexual abuse (Briggs & Hawkins, 2005; Brunnberg, Bostrom & Berglund, 2012; Stalker & McArthur, 2012)

- the heightened risk of assault by professionals or non-parental figures experienced by children with disability, compared to children without disability (Grossman & Lundy, 2008; Hershkowitz et al., 2007).

## Evidence from children and young people with disability about sexual abuse

Despite increasing recognition of its importance, there is limited research involving children and young people with disability that directly canvasses their experiences, views and ideas about safety, abuse and preventing harm. Research about abuse and neglect with children and young people who have non-standard communication is rare (Murphy, O'Callaghan & Clare, 2007). A number of researchers have identified this as a significant gap in knowledge (Dyer & Teggart, 2007; Mepham, 2010; Stalker & McArthur, 2012). This is of concern, given their high risk and the limited avenues children and young people with limited or non-verbal communication have for relaying information about abuse. Those who use sign or symbolic communication systems may not have signs to refer to abuse or behaviour that makes them feel uncomfortable, leaving them without a language to talk about what has happened to them (Oosterhoorn & Kendrick, 2001).

A recent evidence review on abuse of children with disability (Robinson, 2012) located seven empirical studies that directly gathered the perspectives of children and young people with disability, most of which were small qualitative studies. These studies make an important contribution by providing richer, more nuanced insights, but are largely not able to be generalised. In their extensive review of the literature, Stalker and McArthur (2012) found four studies that included the views of children and young people with disability; two of these had sample or methodological limitations. The same four studies were located in the Robinson review.

Briggs and Hawkins (2005) conducted a large study with 116 teenagers with intellectual disability in New Zealand, which found significant levels of violence both at home and at school. Children also told of their reluctance to report abuse and criminal assaults due to 'embarrassment, fear, and a lack of belief that their experiences would be well received or acted on' (p. 24). Students said they found it particularly difficult to report sexual misbehaviour involving their peers, due to embarrassment and fear of retribution. While nearly 80 per cent of young people thought it was unacceptable for adults to use children for sex, 10 per cent were unsure if it was acceptable and 7 per cent thought it was acceptable. Importantly, the researchers also found that children had limited safety skills, and often had unrealistic ideas about how they would escape unsafe situations. A further distinction made by these children was between abuse inflicted by strangers, family members, and older children or young adults. Most participants in this study accepted sexual misbehaviour by peers or older young people (coerced and forced sex, forced viewing of pornography and so on) as the norm, and not worth reporting.

Akbas et al. (2009) conducted research with 20 children with learning disabilities who had been sexually abused, finding that they could consistently provide a thorough and detailed history of their experience.

Higgins and Swain (2010) conducted narrative research with seven adults with disability about their experiences of child sexual abuse. This study highlights the importance of

research that prioritises the voices of people with disability, investigating the impact of abuse on the formation of young people's identities, the pervasive effects of the abuse in their lives and the central role of organisational practices in increasing risk, as illustrated by the following quote by May:

> *Like other disabled people, I lacked a sense of my own body belonging to me, and being private, of not having to be touched if I didn't want to be. This came from having to have many visits to the doctors and physiotherapists, and needing help to do things. I remember being paraded in front of doctors with very little on and feeling like I was a thing for discussion rather than a person in my own right … I can't say this makes us more of a target, but it does make us better victims as we are less likely to object or tell (p. 109).*

Emerging research with children and young people with cognitive disability about belonging and connection reveals mutuality and reciprocity in relationships, a sense of personal agency, being respected and being viewed as having capability as key protective factors in terms of personal safety (Notara & Robinson, 2013; Robinson, 2014). While such factors are similar to those identified by many children, young people with disability faced additional barriers to feeling and being safe. These included feeling like they have to navigate a judgemental public gaze as well as manage interpersonal, family and support worker relationships. Further, they felt that workers and systems gave inadequate responses to their experiences of harm, especially in schools. While the families of young children mitigated their experiences in order to prevent further abuse (for example, stopping going out in public places after being shouted at in supermarkets), this had significant costs for both parents and children.

## Promoting personal safety – safeguards and preventing abuse

Evidence consistently shows that the risk of maltreatment is reduced for children and young people with disability when their dignity and humanity is respected and they are treated as equal citizens, and as valued and included members of their communities (French et al., 2009; UNICEF Innocenti Research Centre, 2007). Such approaches to safeguarding focus on developing relationships, reducing social and physical isolation, and building strong and ongoing formal and informal networks for children and their families across multiple domains (Mepham, 2010; Murray, 2004; Robinson, 2012).

Taking a deficit approach to disability can reduce children's and young people's safety. Goodley and Runswick-Cole (2011) noted the impact of the medical or psychology-driven approach to diagnosing and treating children with disability, which focused on children's deficits rather than the barriers that needed to be removed in order for their rights to be met. There is a particular danger that dominant normative understandings of children, and of child sexual abuse, may exclude children and young people with disability (or include them only partially) in broader initiatives about preventing or responding to child sexual abuse. For example, some research presents the developing sexuality of young people with disability as a rights issue, exploring the nexus between positive expression of identity and the need to recognise the heightened risk that young people with disability face, as detailed above (Higgins, 2010; Higgins & Swain, 2010). Still common, however, is literature that links sexuality and sexual abuse in a less positive manner, relating sexuality primarily to concerns

about sexual health and maltreatment (Griffiths et al., 2004; Jemtå, Fugl-Meyer & Öberg, 2008).

The particular circumstances of children and young people with disability may be poorly considered in broader campaigns about preventing abuse, such as school anti-bullying strategies (Dyer & Teggart, 2007). Children and young people with disability may be inadequately supported to counter peer violence, exploitation and abuse (Briggs & Hawkins, 2005). Also, despite wishing to provide protection to young people, withholding education about sexuality and personal safety leaves them without a language to describe abuse (Gore & Janssen, 2007).

At an individual level, studies have demonstrated the importance of children's and young people's voices in both safeguarding against harm and in responding to abuse. Not only is it crucial for children and young people to have a language to describe harm (Oosterhoorn & Kendrick, 2001), but it is also important to have people in their lives who are prepared to listen to and act on reports of harm. Further, children and young people who use non-standard methods of communication have been found to lack the language to describe their experiences in their preferred communication form (for example, sign language or communication devices) (Murphy et al., 2007; Watson et al., 2007).

A number of researchers discuss the need to build capacity to resist maltreatment at multiple levels – in individuals, within organisations, at the community level and at a broad societal level (Marsland et al., 2007; Stalker & McArthur, 2012). Several studies argue that when resources, attention and energy are focused on prevention at the whole community level, there are benefits for all children and young people with disability, as well as improved responses to those who experience harm (Briggs, 2006; Higgins & Swain, 2010; Robinson & Chenoweth, 2011).

### Responsive action when abuse is detected

The evidence described above demonstrates the need for a firm foundation of support for children and young people to prevent and safeguard against harm. In stark contrast, relevant research about responding to the abuse and neglect of children with disability shows that a series of factors negatively impact children's and young people's likelihood of receiving effective and timely support if they experience abuse.

A reluctance to believe that children and young people with disability experience high rates of abuse has been identified among professionals working in legal, justice and education fields. Despite a gradual shift away from presuming children's and young people's incompetence more broadly, there remains a persistent view that children with disability are unable to give credible and reliable accounts of their experiences (Akbas et al., 2009; Mepham, 2010). Professionals have reported having inadequate support to develop the skills they need to do their job well with children and young people with disability, such as police interviewing skills (Aarons, Powell & Browne, 2004).

The need to address children with disability as a particular group requiring support in mainstream services has been slow to be recognised in a number of areas, including social work and domestic violence support services (Baldry, Bratel & Breckenridge, 2006). Case

managers may be more likely to attribute characteristics to children with disability that contributed to their abuse than to children without disability, and to feel greater empathy towards abusive family members (Manders & Stoneman, 2009). Families and other care providers may be inadequately supported to meet the needs of children and young people with complex support needs (Shannon & Tappan, 2011), leaving them in stressful and distressing positions. Abuse has also been shown to be less recognised in children with disability who come to mainstream services such as hospitals (Kvam, 2000).

## Education and protective behaviours for children

It is critical to empower children and young people with disability to speak up early about concerns they have about possible and actual maltreatment. Education and training for children and young people with disability in a range of contexts (schools, mainstream services, early childhood services and so on) is also essential to prevent and respond to abuse, and is strongly identified in the literature as a necessary response component (Briggs, 2006; Coulson Barr, 2012; French et al., 2009; Khemka et al., 2009). There appears to be scant research directly addressing the personal safety of children and young people with disability.

## Training and protective actions of parents, carers and professionals

A number of researchers address the role of adults in preventing and responding to child abuse. Several studies discuss how parents act to minimise risk and protect their children from potential abuse. Oulton and Heyman (2009) found that mothers of children with complex support needs in particular mistrusted the caring capabilities of others, and had a heightened sense of responsibility for their children's wellbeing and safety. In terms of preventative education, a systematic review of parental attitudes to child sexual abuse prevention education for children with disability consistently found that parents were unsure about when and how to deliver abuse prevention messages to their children (Hunt & Walsh, 2011). Many parents lacked the confidence, vocabulary and resources, and omitted the most crucial factors while focusing on less important concepts, such as warning of stranger danger but not inappropriate touching from personal care providers.

Briggs and Hawkins (2005) discussed education programs that aim to prevent abuse, reporting effective results from comprehensive, explicit programs that also involve parents (building on the findings of earlier work by Finkelhor et al., 1993). They stated that children reported incidents more quickly and felt more positive and empowered about their actions after education (although it was not preventative). They also suggested expanding the initiative then underway in New Zealand where Police Education Officers delivered safety education, as it was well received by the young people in their study, relieved teachers of the need to develop additional skills, and overcame the omission of critical information in protective behaviours training due to teachers' embarrassment or fear of receiving disclosures.

For those children and young people who need formal care, the literature recognises the need for workers to have adequate resources and support. Part of this support includes training and professional development for professionals, across a wide range of areas,

focused on including children and young people creatively and respectfully (Astill et al., 1999; Coulson-Barr, 2012; French et al., 2010).

## Intersection of research with national policy

The research reported above intersects with a national policy environment in which the rights and needs of children and young people with disability do not appear to be thoroughly considered. A clear need can be seen for existing and proposed research to better inform the rollout of child protection and disability policy:

- The *National Framework for Protecting Australia's Children 2009–2020* includes a small number of initiatives and policy actions specifically related to children and young people with disability. The second three-year action plan (2012–2015) includes actions seeking to link key policy and practice development in the disability arena with violence prevention policy and practice, and to build evidence on the harm experienced by children with disability (2012). This research represents an opportunity to add to the third action plan.

- The *National Plan to Reduce Violence against Women and their Children* has included some specific project work on stopping violence against women and girls with disability.

- The Department of Education and Training's *National Safe Schools Framework* does not recognise children with disability as a group who experience higher rates of harm.

- The *National Disability Strategy 2010–2020*, agreed on by all levels of government, is the framework designed to support the development of the principles of the UN Convention on the Rights of Persons with Disabilities into policies and programs for people with disability, families and carers. Each state jurisdiction has, or is currently developing, an individual plan to translate the strategy's vision into tangible and measurable service improvements.

- The National Disability Insurance Scheme (NDIS) articulates this high-level policy, and promotes the safety of children and young people to varying degrees.

- The recently reviewed *National Standards for Disability Services* includes a focus on preventing abuse.

- The *Disability Standards for Education* discuss a variety of abuse, but await the consolidation of Commonwealth discrimination legislation.

Safeguarding, preventing harm, and protecting and promoting personal safety need to be reflected in the development and organisation of policy and practice at the broadest level, and these principles need to be held consistently as policy gets more localised.

This connects directly to research, policy and practice on the importance of building on the protective elements of inclusive relationships, networks and communities for children and young people with disability. At the community level, engaging bystanders to take action against abuse and neglect of children and young people with disability may be a way to

broaden the base of support in both preventing harm and in ensuring that it is effectively responded to when it happens. Bystander action is generally aimed at three different levels: at stopping a specific incident of violence; at preventing the risk of violence escalating; or at changing the systemic conditions under which violence occurs (Powell, 2011). Research with school students addressing bullying (Twemlow et al., 2004) and sexual coercion (Rigby and Johnson, 2004b; 2005; 2006) has demonstrated the effectiveness of bystander strategies that engage all stakeholders rather than focusing on individuals or on one group (such as students) (cited in Powell, 2011).

## Conclusion

The gaps in the research emerging from this review underline that abuse research has paid little attention to the perspectives of children and young people with disability; to preventative and safeguarding approaches; or to factors that promote personal safety for children and young people with disability.

## 2.2  Research findings

**Key points**

What does 'being safe' mean to children and young people with disability and high support needs?

- Children and young people provided a wealth of information about what 'being safe' meant to them, both in conversation with the researchers and through their maps. This included:
  - feeling safe and secure
  - being protected
  - not being hurt
  - not trusting strangers
  - following rules – written and unwritten
  - having strategies
  - having some control of the situation.

- Children and young people also pointed out that it can be very hard to know what is safe or unsafe, especially for children and young people with higher support needs. They talked about complexity in relationships, when some people were trustworthy on some occasions but not others. Few remembered learning about safety, either at school or anywhere else.

- Families and professionals all viewed the children's and young people's understanding of safety as limited. A common theme raised was that the ways in which service systems operate make it very difficult for children and young people with high support needs to identify trustworthy and untrustworthy people in their lives. They saw a lack of safety (self-protection) skills in their children or clients – in some cases feeling that these could not be learnt, and in others that they were developing slowly.

What helps and hinders children and young people with disability and high support needs in feeling and being safe in institutional settings?

- Children and young people described a series of factors that helped them to feel and be safe. These included having a secure foundational space (home), having friends, feeling known and valued, having someone to confide in, avoiding contact with people they didn't know, telling someone if they felt unsafe and having appropriate opportunities to learn about how to be safe (both formal and informal).

- Things that made it difficult for children and young people to feel and be safe included fears and worries about their safety, feeling out of control in situations, the impact of having experienced various forms of abuse, peer-to-peer abuse, being under-supported through transitions, and complexity in their family lives.

- Children and young people and their families described fairly stable environments that had not changed markedly – mainly comprising home, school, and vacation care or respite support. As young people left school and entered young adulthood, some related a sense of increasing confidence and capability in their safety skills. Others discussed new risks due to pressure from peers to engage in risky activities such as drinking and drug-taking. Families and professionals talked about the continuing reliance of people with high and complex support needs on the service system, in a climate of increasing casualisation that meant they were exposed to higher numbers of little-known workers.

How do people who provide support perceive and respond to children's and young people's concerns about their own safety?

- Families had a limited knowledge of the actions that children and young people took to keep themselves safe, and mostly felt that their children did not, or could not, act to keep themselves safe. Professionals commented on a greater number of people, but did not know them as well. Both families and professionals related similar views about the ways in which children and young people acted to keep themselves safe, including using safety strategies and relying on established networks.

- Families and professionals spoke in detail about the actions they took to build a sense of safety with and for the children and young people. These included providing a loving foundation, building capability and confidence, building networks of extended family and friends, putting support into place, focusing on education and communication, managing relationships with staff members, and taking action on behalf of the children and young people.

- Families and professionals outlined ways in which they felt the children and young people risked their personal safety, centring on the individual qualities inherent in their characters and impairments, lack of knowledge, and risky social practices and relations. Families and professionals also described how they as supporters responded to these risks and potential harm – by worrying, focusing on prevention, managing risks and taking action to prevent harm, respond to risk factors and respond to harm when it occurred.

- Finally, families and professionals commented on the limited degree to which they felt systems recognised children's and young people's perspectives of safety. This was because of the high number of staff members children and young people do not know, the fact that their needs were poorly met in schools, and services' lack of focus on disability support needs and poor risk orientation.

The institutions in which children and young people with disability frequently spend a high proportion of their time influence the context of the findings. Children and young people in

this research had weak affiliations with mainstream institutions, apart from school. Most children and young people in this study predominantly used services specifically for people with disability – special schools or special units within mainstream schools, disability support services (including community support, vacation care, after-school care, respite, employment and group home services) and therapy services. The mainstream institutions with which they engaged included school, vacation care, OOHC, a drama group and church (in the company of family). A series of other community institutions that might have been expected to feature in children's lives were not mentioned, such as scouts, sports, leisure and recreation, and music groups.

## What does 'being safe' mean to children and young people with disability and high support needs?

Many of the children and young people in this study could not easily determine the concept of 'being safe'. Safety is an abstract concept and is difficult to explain for people who require concrete concepts to aid understanding. As well as discussing the ways in which they understood safety, children and young people pointed out that it can be very hard to know what is safe or unsafe, especially for those with higher support needs. Safety can be very complicated, particularly when it concerns relationships with people who are involved in children's and young people's lives. For example, two children living in OOHC named their parents as safe people, although service providers said their home life had been unsafe. One child felt two teachers were untrustworthy based on the activities they had done with kids at school (boxing and throwing water balloons). Three older young people talked about the complex relationships they have with family members, and how they are sometimes 'trusted adults' and sometimes not. Few children and young people recalled any formal learning about safety in school or disability support services, and of those who did, only one had a detailed recollection of what he had learnt.

> *Has anyone ever talked to you about being safe?*
> Yeah, it was when I was back in school we had lessons.
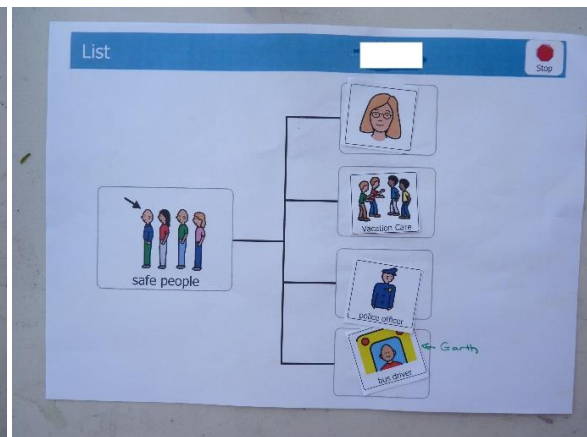> *Do you remember what they taught you?*
> Not really, because after high school my mind is like not working. Well it is, but just not sometimes.
> > *Dee-anne, aged 18*

As far as could be ascertained, the three children with very high support needs involved in the project did not have a language for safety concepts, or communication tools or programs to support them to develop these concepts over time.
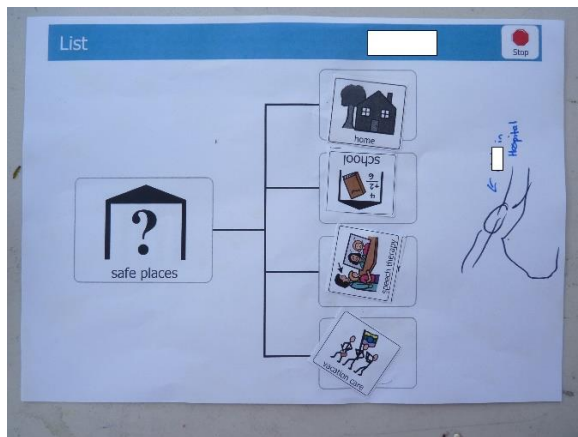
*My safe places – by Robert, aged 9*    *My safe people – by Robert, aged 9*

## Perspectives of children and young people

When provided with the opportunity, and inviting and appropriate communication tools, children and young people provided a wealth of information about what 'being safe' meant to them, both in conversation with the researchers and through their maps. Many children and young people used physical safety as a starting point in their conversations about safety, and moved from discussing keeping doors locked, staying off the road and so on to talking about relational safety. This included feeling safe and secure, having access to help from trusted adults, not being at risk of harm, and having safety strategies and the opportunity to put these into operation.

### Feeling safe and secure

A number of children and young people equated being safe with feeling safe and secure. This was articulated with regard to both places and people.

Most children and young people said that being in places they knew provided a sense of safety and security. Home was the most strongly represented, and also school and disability services. Importantly, having a level of control over what happens in these places made a difference to how safe children and young people felt (see below).

Particular people were central to providing feelings of safety and security. Family, especially mothers, were of core importance to most (but not all) children and young people. Support workers were also nominated by many children and young people, connected to their personal qualities – that is, they nominated the workers who they liked and whom they felt liked them.

*Mummy and Nan – by child, aged 9*
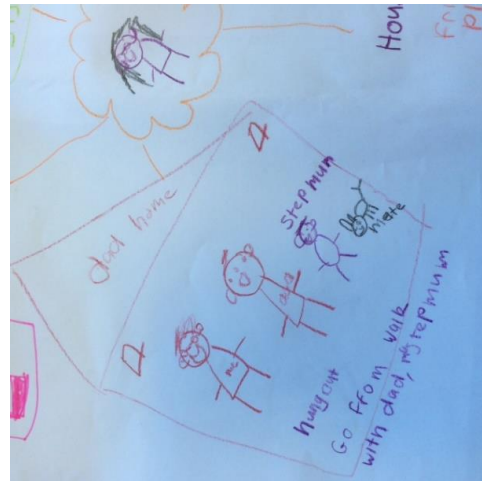


*Dad's home – detail from Rachel's map, aged 25*

*Dad's home – detail from Rachel's map,*

### Having a go-to person

Having an identified person or people who were seen as trustworthy and reliable emerged as a clear theme in interviews with children and young people. Almost all identified more than one safe person in either pictorial maps, the safe people domain activity sheet or interviews. Almost all children and young people nominated mothers as safe people, including two who lived in OOHC. There was a distinction between the way children and young people discussed family (predominantly mothers, but also fathers and extended family members such as grandmothers) and professionals. Relationships with professionals were less strongly established, and children and young people did not always name the people who they said were trustworthy, talking about them instead by role (for example, 'my teacher' or 'my support worker'). Nominated people working in institutions included teachers and key disability support workers. A small number of children and young people



also named school counsellors, staff members in shops and volunteers at community centres. These people shared particular qualities – they were known and liked, and children and young people felt that they were in turn well regarded.

*F, the support worker – detail from Grace's map, aged 14*

## Being protected

Some children talked about safety in terms of being protected, and perceived that their family took this role in their life. Dogs also played a protective role for a small number of children in the study in helping them to feel safe. Two participants talked about how hospitals made them feel safe – one because he had recently been treated for an injury there, and the other because she had been impressed by the caring qualities she had seen in staff members when she had visited relatives in hospital, despite never having been a patient herself.
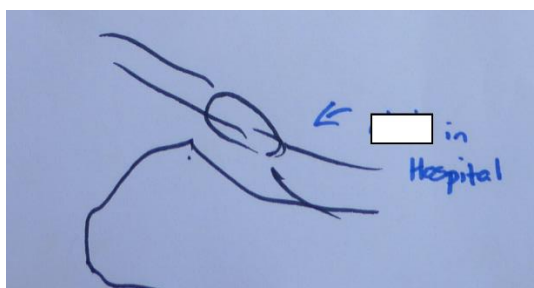


*Robert in hospital – detail from Robert's map, aged 9*

## Not being hurt

Many children and young people talked about how they understood being safe as the absence of threat and harm from their lives. Children and young people who were able to articulate the experience talked almost universally about feeling scared, being bullied or experiencing peer-to-peer harm in institutional settings. A child with physical disability worried about being accidentally hurt by other children, particularly as he relied on others for assistance to move from one space to another. Family members of children and young people with very high and complex support needs also reported incidents where their children had experienced harm from other children, both accidental and due to assault from others who also had significant support needs.

> At high school I went to ____ High. At times I felt safe, but some days I just didn't feel safe.
> *What was making you not feel safe on those days?*
> Just how some people act or what they do. Physical things and mental, like mucking up, bullying.
> *Francis, aged 19*

## Not trusting strangers

Several children and young people said that they were alert for strangers, had stranger danger awareness or did not trust strangers. No children or young people showed an awareness of risk minimisation strategies to evaluate whether someone they didn't know or someone they knew in a professional or personal context might pose a risk to their safety.

> *What do you think are the things that can make kids unsafe?*
> Stranger danger.
> *What does that mean?*

It means a stranger has a secret weapon … puppies.
*Tell me about that?*
It means children love puppies and they use puppies to get the children to come to them.
*Eric, aged 9*

### Following rules – written and unwritten

Children and young people provided many examples of the rules they followed to keep themselves safe. Some of these were formalised, such as school or workplace rules and procedures, and others were unwritten rules that they adopted to go 'under the radar'.

Most children and young people mentioned road safety as being important in keeping safe. This was in ways both consistent with non-disabled children of their age, and also in ways specific to having cognitive disability – for example, where they had experienced running onto the road in panic due to overwhelming anxiety arising from their autism, or where they could not bring themselves to look at the road or cars due to a previous experience they were unable to name.

'Sensible' behaviour was discussed by a small number of children, who offered ideas such as changing clothes if they are cold and not running through common areas where they might knock other people over. Young people raised this topic much more frequently. Their ideas for behaviour that would keep them safe included not taking drugs, not drinking alcohol, not hanging out in the street, not going to a particular regional town (because rough people go there), not looking 'gangsta' and not making eye contact with people in the street.

Don't look at people in the street who are in your face.
*Rachel, aged 25*

Together, these comprised quite a significant number and range of restrictions on the behaviour of some teenagers and young adults. The maps and interviews with young people indicated that many of them followed their own advice, taking a number of measures to reduce their visibility and proximity to possible harm. They reported that a number of potential dangers in public places were at the root of these actions, including discrimination, bullying, violence and even hate crime against young people with disability. While they didn't speak about dangers in institutional spaces, children's and young people's reactions may carry over into institutional spaces, increasing their potential vulnerability to predatory abuse.

### Having strategies

Almost all children and young people spoke about strategies they felt were helpful in keeping themselves safe. Three kinds of strategies were discussed – managing feelings, ensuring physical safety and seeking help.

For younger children and people with higher and more complex support needs, strategies often centred more on managing feelings than responding to external threats. For example, one young person talked about how much he loves his dog, how much comfort she brings him and how she helps him feel less anxious. When he feels very overwhelmed or anxious, he said he sometimes goes to sleep in the dog kennel, a place where he feels safe and secure.



*Having a cuddle with Bella – by child, aged 11*

Strategies children and young people shared for making sure they were physically safe included being able to lock the door, having someone with them when they walk somewhere, not taking off their seatbelt while the car is moving, having a phone and keeping it on and, for the small number of people who went out independently, 'having a plan B'.

Finally, a number of participants identified the importance of knowing whom they can ask for help if they do not feel safe or if something is not right. Several children and young people talked about their mothers, and also named school teachers and key support staff in holiday care, respite and day support services who they felt they could talk to, based on the existence of a trusting relationship. A number of children and young people mentioned the police, primarily talking about how they could call 000 in an emergency.

### Having some control of the situation

Linked to above, some children and young people expressed the importance of being able to use their strategies. In order for this to happen, they needed to feel listened to, and that they had a level of influence over what was happening or might happen. The children and young people who had experienced living in OOHC demonstrated this particularly clearly. One young person had struggled with the effects of severe trauma for several years, which required (among other things) a highly reliable and consistent support network between home, school and child protection services in order for her to be able to leave her house with any degree of confidence. Two others said they did not understand what 'safe' meant, although both had otherwise quite strong receptive and communication skills.

A small number of children also talked about other children being safe from their actions, and spoke about safety in the context of keeping control of their own behaviour. These children, and one young person, talked about not walking in front of cars and not hurting other people.

> *What does safe mean?*
> Not hurting people, not biting them [Jane demonstrated by biting her own arm].
> > *Jane, aged 14*

Several children and young people discussed or demonstrated the importance of understanding what, how or why things were happening in their lives. This related to both big things – like changes to their OOHC placement and being suspended from school or work – and also to routine things, like the choice of activities and rostered staff.

> I didn't feel safe at ____ High because they kept suspending me and sending me home. I was bullied there, most of the time by the boys, sometimes me bullied them …
> *Is it okay to talk about what kind of bullying?*
> Yes. They would slap my face, kick, punch and spit. I got in the car to go home one time with Mum and this guy spat on my face. I was crying and Mum said 'You're never going back there'. So I went to [special school].
> > *Domenica, aged 19*

There was surprisingly little differentiation between participants' responses according to gender. Boys and young men were very forthcoming in discussing their concerns and fears about safety and harm, and girls and young women spoke equally about the areas in which they felt confident and strong. However, consistent with previous research (Frohmader et al., 2015; Dowse et al., 2013), more young women mentioned their experiences of sexual abuse, assault and harassment.

It is, however, an acknowledged limitation of the study that – due to its focus on safety rather than abuse and the attendant ethical issues – there is inadequate data to understand differences in the experiences of violence related by female and male children and young people.

## Perspectives of supporters

Families and professionals all viewed the children's and young people's understanding of safety as limited. They expressed shared concerns about how the ways service systems operate make it very difficult for children and young people with high support needs to identify safe and unsafe people in their lives (see below). They saw a lack of safety (self-protection) skills in their children and clients – in some cases feeling that these could not be learnt, and in others that they were developing slowly.

### 'Trust radars' broken

Several professionals pointed to the ways in which multiple service systems interfere with what one person called the 'trust radar' of children and young people with high support needs, impairing their understanding of what is safe and not safe:

> From a very early age [he] has been exposed to many more strangers and many more that invade his personal space than other children. This has already broken his trust radar, we teach him to trust anyone …
> *Lee, speech therapist*

For children and young people who rely on physical personal care, this extends to sometimes quite intimate touch. Without contextualising education or strong protective mechanisms, as one disability support worker asked, 'How do you know what hands on you are meant to be doing or not doing?'

### Skill gaps increase the risk of harm

Most family members talked about the ways in which their children understood safety in relation to their own fears and worries for their children. They spoke about the personal qualities they saw in their children that made it more difficult for them to stay safe – that they are trusting, open with people, easily manipulated and easily led into trouble.

Connected to this was a consistently held view that the children's and young people's limited skills could result in them experiencing harm. Examples provided included a lack of skill with roads, a lack of awareness about exposing underwear in public, masturbating in public, and a more general lack of knowledge about wider surroundings and possible threats. Over half of the participants in this research had previously experienced harm of some form in institutional contexts. In a number of instances, families were fearful about further harm befalling their children, rather than expressing an abstract concern about possible harm that might befall them.

> She wouldn't have a sense of lack of safety. She knows what it is to be scared of bugs or something – she screams and tells you to kill a bug if it's anywhere near her … But as far as being unsafe, I don't think she has any idea.
> *Helen, mother of Jane, aged 14*

A number of professionals felt that the children's and young people's knowledge was situation-specific, and that they were often unable to transfer their knowledge or skills into new contexts. This was discussed in terms of transitions – particularly from school to work, and also from primary school to high school. Two disability support workers also felt that a lot of people they worked with understood safety in an immediate sense (for example, they weren't under immediate threat of being hit), but were not able to assess whether they were in a safe environment in a broader context (such as whether new associates were trustworthy, or being aware of the wider street scene). Two workers felt that children and young people lacked capacity in putting skills into practice, saying 'they can talk the talk, but are not very good at walking the walk'.

## Developing skills

Families and professionals expressed a range of perspectives about how children and young people either take up strategies or develop their own understanding of safety. Some families said their child had no understanding of safety. One mother said her daughter 'follows what we tell her to do, but doesn't understand the why', and felt that her daughter was unable to learn anything about her own safety. Another two mothers talked about how their children were experiential learners and provided examples of role-plays, practice scenarios and videos they had used to help their children learn about safety in common situations in their lives. One family member talked about her son becoming more aware and able to navigate safety issues as he grew into young adulthood, saying 'he's got instincts about things now'. For children with very high and complex support needs, families and professionals pointed out that it is difficult and sometimes impossible to know how they perceive safety.

# What helps and hinders children and young people with disability and high support needs in feeling and being safe in institutional settings?

The first part of this section details the study's findings about the factors that children and young people said helped them to feel and be safe. The second part of the section describes the factors that children and young people felt hindered them in feeling and being safe in institutional settings.

## Factors that help

Children and young people described a series of factors that helped them to feel and be safe. These were related to having a secure foundational space (home), feeling known and valued, having someone to confide in, not being exposed to strangers and having appropriate opportunities to learn about how to be safe (both formal and informal).

### Home as a foundation

Most, but not all, children and young people emphasised their home as a sanctuary, where they retreated from stress and distress, and regenerated their energy. For most, home was a safe space with safe people. While it is a private space rather than institutional, the fundamental importance of home and the role that it plays in establishing and maintaining children's and young people's confidence, wellbeing and resilience cannot be uncoupled from an understanding of safety in institutional settings.

*My room – by child, aged 9*



### Friendship

Children and young people described friends as being important in two ways – first, for helping them feel better about themselves, and second, as a protective support that stopped them from having to go to places alone (safety in numbers).

However, of the children and young people who talked about friends, relationships were described in fairly shallow terms – only as in existence, rather than as embedded in the patterns of their lives. For example, only one child talked about going to friends' houses to play, or included them on their maps as safe places. A small group of young people discussed friendship in more depth, and, for them, their friends' support created a network that built a sense of confidence and security – they socialised regularly, spent time at each other's homes, and relied on each other's families for transport and social support. One person in this subset also talked about the importance of being a friend to his friends, and giving advice and support.



*Detail from James' map, aged 20*

### Feeling known and valued

Children and young people expressed their views in multiple ways about the impact of positive relationships in the institutions that were central in their lives. For some, the behaviour and manner of other people helped them to assess how safe or unsafe a place might be:

> *How about [disability support service]? Today was your first day; did you feel safe there?*
> Yeah, I felt safe. The people were nice, the people were calm.
> *So is it when people aren't calm that you don't feel safe?*
> Yeah, if people are in a really bad mood I don't feel any good.
> *Francis, aged 19*

For others, having established and positive relationships with trusted support staff made them feel confident that they would be listened to if they had a problem because they were known and valued. A number of children and young people identified particular individuals based on their personal qualities. They said that they would talk to these people because they like them and because they are receptive to what they say.

> I would tell Anna [service coordinator] if I wasn't safe. She listens to me.
> *Robert, aged 9*

Some children and young people with higher support needs were observed to engage with more warmth and animation with workers they knew better, and several children and young people included pictograms of workers they knew well as 'safe people' in their activity sheets.

As well as knowing the people, the place and routines – being, in Rachel's words, 'a part of the furniture' helped some children and young people to feel safe. This created a sense of community and belonging for some, although other young people struggled in navigating the tensions between disability support services and the wider world (as described in the next section).

Several children and young people described having a solid support system behind them that built their confidence and helped them to feel comfortable and confident in a range of institutional settings. For example, Jane said school was a safe place for her, and drew her teacher and friends on her map. She also added her sister and parents to her map, and a supported regular activity at the local neighbourhood centre, saying 'I love Gail and Emily' [the workers there].



*Detail from Jane's map, aged 14*

## Avoiding contact with strangers

Many children and young people talked about stranger danger. They said that not trusting strangers or people they did not know helped them to stay safe. Two children had recently watched a YouTube video about a test situation where an unknown adult tried to get children to go with him into a park, to show parents how easily children could be enticed by looking at puppies, and this was fresh in their minds. Two young people talked about how they sometimes felt unsafe at the bus stop when they did not know who was coming or if someone stepped in close to them.

Other teenagers talked about how they limited contact with people they did not know to avoid the possibility of conflict. After having negative comments made about her in the street, Rachel said she keeps her eyes down and crosses the street or moves away if she sees those people coming in her country town. Paul talked about how there are places he

won't go, and clothes he won't wear, so that he doesn't attract attention from people who might bash him.

While some of these strategies are logical responses to threats, they also result in the children and young people making themselves less visible in the world.

### Telling someone

Children and young people commonly reported that it helped to tell someone if they felt unsafe. However, while it was generally agreed that it was better to let someone know, children and young people needed a person who could be trusted, encouragement to talk, and for something to be done about the problem in order to feel that their safety had been adequately taken into account.

Francis talked at length about how he was bullied and harassed at school, and how miserable and depressed this made him. He did not feel able to talk to his mother about it much, as he thought this 'would make more trouble'. He talked to his teachers and the principal, and said that helped a bit but didn't stop the peer-to-peer harm. Telling the school counsellor helped a lot more because he was given strategies to deal with the bullying as well as support to counter the harm.

> School kind of helped me out, but they didn't help the bullying side, so it kept happening. But I learnt how to handle it better from the counsellor.

### Learning from experience

Young people commented that their perspectives on safety had changed as they had grown older, and they felt that they had developed better skills, understanding and instincts about personal safety as they developed into young adults.

James talked about the developmental approach that his family took to helping him learn how to be safe, and how he started with very limited amounts of freedom, building to greater independence because his parents 'know they can trust me'. Francis spoke very articulately about how he felt that he had developed the ability to listen to his instincts, and his view that it gets easier to talk about difficult issues such as safety as you get older:

> I guess when you're a kid you don't really talk about your problems, but when you get older it's better to talk about it, if you're encouraged to.

### Being educated about safety

A number of children and young people identified the importance of knowing about how to be and feel safe. Conversations with children and young people across the age spectrum revealed a wide range of perceived education needs. For some, knowing about safety was connected to strategies (calling emergency services or knowing martial arts). Feeling

confident about knowing what to do helped, to the point where children could manage chronic anxiety with jokes about what they would do.

> *If you were not safe, what would you do?*
> Ring 0000000. Just 3 x 000 is all you need [drawing on the map].
> *What if there was no phone?*
> Dig a hole to hide in.
> *And if you couldn't dig a hole in the street?*
> Tell [my dog] 'do a runner home!'.
> *Really, who could help you in the street?*
> A shop owner, go to the shop. Foodworks is the perfect place.
> *Why is that the perfect place?*
> Know the people.
> > *Eric, aged 9*

Others, particularly young women, felt education about safe sex and relationships was necessary to feel confident and secure. The young people who were reaching the age where they were able be left alone at home for periods of time were focused on education about how to stay safe at home (for example, keeping doors locked, learning fire safety and knowing what to do if they thought there was an intruder).

## Factors that hinder

Things that made it difficult for children and young people to feel and be safe included fears and worries about their safety, feeling out of control in situations, the impact of having experienced abuse of various forms, peer pressure, being under-supported through transitions and complexity in their family lives.

### Fears and worries

Many of the children and young people involved in the study expressed fears and worries about their safety. These fell into two categories – high-level risks that were unlikely to happen to them, and everyday experiences that made them worried or afraid.

Several children and young people articulated a fear about being attacked by strangers. This included getting robbed at the ATM, getting stabbed by a stranger, being kidnapped on the bus and a burglar coming in when they are home alone. One young person raised a fear of being sexually abused, saying they saw this on the TV news a lot. Other young people in the small group agreed that this also worried them.

> Well, one of the main things, you might have heard this a lot, is stranger danger. Keep away from strangers, and if they ask you to take a lift, just don't get into the car.
> > *Francis, aged 19*

A number of the children's and young people's everyday experiences made them fearful of certain people in their lives, such as teachers who shouted at children, people at bus stops

(both those who behaved erratically and anyone they didn't know), and other children and young people with challenging behaviour.

> The principal let me in her office because [another child] was violent.
> *So they have rules at school to keep you safe?*
> No violence and not injuring stuff.
> > *Eric, aged 9*

## Feeling out of control

Children and young people said that feeling, and having, a lack of control over what is happening makes it difficult for them to feel safe. For some, this was linked to the characteristics of their impairment, particularly for those children who lived with anxiety disorders and autism. In some cases, lack of control was linked to the operations of disability services. One young person talked about how frightening she found it when people she didn't know came to the group home in which she lived late at night. Another had been suspended from work after being involved in a significant incident. After a week, she had not had contact to know whether she would be able to return, or was fired, and found this very distressing.

For others, peers' actions took away their control over how safe they felt. For example, Trevor told the research team about two other students hacking into his computer at school and changing his access password. He took the computer to the IT support staff, who took it away to investigate. The students were eventually caught and punished, which gave Trevor a great deal of satisfaction. However, he spent over a month not knowing what level of access they had to his computer, whether they still had access or whether they could post maliciously on his Facebook account. He also didn't have access to the computer he needed for his own schoolwork. The actions of other children and young people with challenging behaviour also concerned a small number of other participants, particularly one child who was reliant on others to move him due to physical impairment, and worried about being hurt accidentally or on purpose by kids who were racing around:

> To be safe, you need not to destroy things. The Wii room [at vacation care] is the safest, because there are good activities, and the kids are doing things, and not just mucking around.
> > *Liam, aged 10*

## The impact of abuse

In the school context, a significant number of children and young people discussed bullying, harassment and assault. A number of others were not able to independently raise issues due to their level of impairment, and we did not raise lack of safety with them.

Because they lived a more independent lifestyle (travelling to and from disability services by themselves, for example), older young people interacted alone more often with people they did not know. They all talked about negative interactions that involved casual cruelty and

verbal abuse by people in the street and acquaintances (someone they had met in a pub), which had a significant impact on their confidence, self-esteem and sense of worth.

Teenagers talked about the impacts of bullying in a similar way:

> I was bullied a lot, things like name-calling. That was about it. I was called stupid, ugly, idiot. I was in the support class type of thing. Some of the kids in my class said that, and the other mainstream kids. I don't miss school, didn't like it.
> *Dee-anne, aged 18*

While the experiences occurred in different domains, children and young people were quite consistent in their view that the responses by those in authority were frequently either limited or lacking in effectiveness. A number of children and young people recalled teachers telling them to 'suck it up' or 'ignore it' when they were bullied or harassed by peers. In some cases, children and young people perceived that action taken in response to situations was unfair, particularly when they had been suspended from school, or when the people who had abused them did not received any punishment for their actions. Finally, there appeared to be a lack of follow-up to support children and young people to recover from the impact of this abuse.

These negative interactions created a climate in which a number of children and young people mistrusted particular adults in key roles. While several children and young people talked about times when it was clear that they, or situations around them, were not safe (such as when they were physically injured or bullied), it was much more difficult for them to articulate uncertainty or disquiet, particularly about people in authority. Robert said that he felt unsafe around three teachers at his school, who were mean to or yelled at children (not necessarily himself). He said he would tell other kids if he felt unsafe, but would not tell teachers. He did say, however, that the principal's office was a safe place, and somewhere he would go. Sometimes teachers' actions and activities strongly influenced the children's and young people's degree of confidence in them. For example, one child said that he could not trust a teacher who did boxing, or another who threw water balloons.

## Peer pressure

Young people, in particular, talked about the negative effects of peer pressure in their lives. A small number described significant risks in their lives. Francis put it well:

> If you want to fit in with the group, sometimes you do things you shouldn't.

One young person learnt a hard lesson about getting into cars with people they did not know well when they had a terrifying high-speed ride with a drunk driver and also had money stolen.

## Under-supported transitions

Children and young people raised a number of experiences in which they had felt unsafe, including making transitions from one school to another, to a new geographic area, to a new disability support service and out of the OOHC system.

At best, one participant said moving from one school to another made them nervous for a little while, which settled down. However, for four children in the research, experiences of bullying and assault drove them to move schools.

All except one participant in this research were in either special schools, or units or segregated classes within mainstream schools, which increased the likelihood of moving outside of the local geographic area and having to go to a school other than the local primary school or high school. Participants also reported experiencing this disconnection between people and place when leaving school, and when transitioning from OOHC at age 18.

One young person in the study had recently left care, and talked about how isolated he felt moving to a new geographic area, moving from a domestic family arrangement into a group home, and moving from school into a disability support service all at once. He missed his friends terribly, and said he had not had any opportunity to see them since leaving care.

> I felt safe, comfortable in [place]. I worried when I had to move out, that I mightn't be safe anymore.
>
> *Trevor, aged 18*
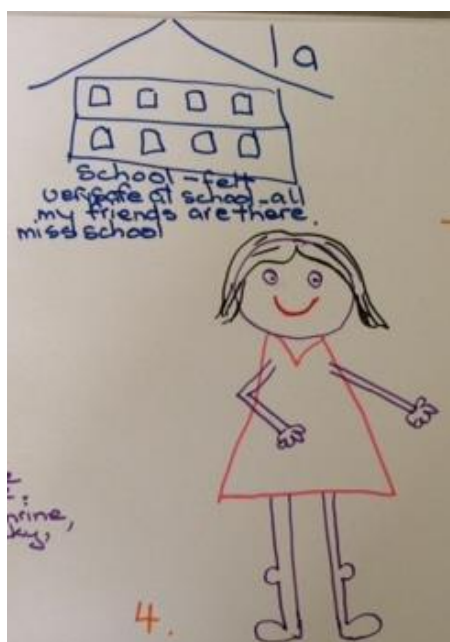


*Detail from Claudie's map, aged 18*

Complexity in family life

For some children and young people, family were not named as safe people, and home was not named as a safe place. Four children and young people in this study were living, or had

lived, in the OOHC system. In addition, another four discussed tensions in this domain that seemed to affect their feelings of safety and security.

## How do people who provide support perceive and respond to children's and young people's concerns about their own safety?

Families and professionals responded to a series of questions about how they perceive and respond to the children's and young people's concerns about their own safety. They spoke in detail about the actions they took to build a sense of safety with and for the children and young people. They outlined ways in which they felt children and young people risked their personal safety, and described how they as supporters responded to these risks and potential harm. Finally, families and professionals commented on the degree to which they felt systems recognised children's and young people's perspectives of safety.

### How do children and young people act to keep themselves safe, and what do they do if they feel unsafe?

Families had a limited knowledge of the actions children and young people had taken to keep themselves safe. The most common response from family members was either that they had not thought about this, or that their children did not, or could not, act to keep themselves safe. Two mothers, for example, talked about the impulsivity and anxiety that is a hallmark of their children's impairments, and how difficult this made it for them to manage their own safety. Professionals took a more global view of how children and young people acted, and commented on a greater number but knew them less well.

#### Using safety strategies

Families and professionals raised a number of different strategies that children and young people used when they felt unsafe. However, they also identified a range of tensions that they felt children and young people regularly dealt with that made it hard for them to know what to do, or to take action to keep or feel safe.

Strategies fell into three types:

*Action.* Several families talked about disclosure strategies their children had used, focusing particularly on occasions when their children had talked about peer-to-peer harassment, bullying and violence at school and in disability services. One parent was pleased to hear about her son's increasing capability to act on his own concerns when he discussed blocking someone on Facebook whose comments made him feel uncomfortable. Disability support workers also talked about other young people who had taken down their Facebook pages after being cyberbullied.

Disability support workers talked about how several young school-leavers who used a support group had active strategies to ensure they knew where to seek help. They have the Lifeline number saved in their phones, and a number have sought help from the police, even

when it may not have been an emergency situation. A small number of family members also talked about the children's and young people's ability to call family members, emergency services or other support services if in trouble.

> *What do you think Francis would do if he felt unsafe?*
> Hopefully protect himself and do what he needs to do, ring me or, as he says, ring the police. I think he's clear about the rules.
> *Monica, mother of Francis, aged 19*

One young woman had taken a proactive approach to her own emotional safety throughout her teenage years, seeking assistance from a psychologist (with her mother's support) to help manage very complex support needs arising from trauma. During particularly difficult times, her connection to a friend also made a real difference.

*Avoidance.* Three families talked about how their children avoided discomfort or feeling unsafe by putting their head down, covering their face with their hair, avoiding looking at the object or person, going to sleep or running off. Professionals talked about children and young people retreating both physically and emotionally. This increased the risk to them – either physically because they became lost and distressed, or froze and could not move out of the way of a violent situation, or emotionally because they shut off and replayed situations in their heads.

*Resistance.* Behaviours of resistance were not always easy to interpret. School resistance in particular was an issue for some children and young people in the study. When part of a bigger pattern of challenging behaviour, it was very hard for their families to get to the root of what was making them feel unsafe.

Families felt that action strategies used by their children were generally effective, when implemented. The more common avoidance and resistance strategies, however, arose from anxiety and trauma responses. These were more difficult for children and young people to endure, and also harder for families and support professionals to resolve.

> If Eric realises he is lost, he gets so anxious that he can't tell you anything. If you asked him a question when he is anxious to a certain level, he can't speak anymore.
> *Olive, grandmother of Jules, aged 11, and Eric, aged 9*

Some disability support workers commented that they worked with young people who came from school with some knowledge about what they were supposed to do in situations of potential risk, and what not to do, but lacked practice. Connected to this, workers in another service said that some children and young people they worked with knew what to do but did not remember it when they were under stress and needed it.

Families and professionals raised peer pressure and manipulation as a difficult tension for children and young people who were more independent. Support workers in disability and holiday care services talked about young people being emotionally manipulated, having money 'borrowed' and experiencing cyberbullying.

Relying on established networks

Professionals commented on the support networks that surrounded many children and young people, and their role in helping them feel and be safe.

> Sometimes people have that thought that they are incredibly independent or they are being independent where they are safe. They may not be doing things that keep them safe but other people are helping them to be through the network. There is this silent army of supporters and I think that can happen in a lot of places.
> *Fiona, disability services manager*

Consistent relationships were seen as very important, as they supported children and young people in being known. They were viewed as particularly helpful for children and young people with minimal verbal communication skills or idiosyncratic behaviour. A therapist commented that 'when you get to know children and young people, you can get clear signals about what they want and don't want, regardless of their capacity for speech'.

Some family members felt that their children did not have the capacity to take self-protective action, and some children and young people in the research had such complex support needs that it was highly unlikely they would be able to independently initiate self-protective activities without sustained, long-term education from workers and others around them.

## How do you build a sense of safety with and for children and young people?

Families' and professionals' responses centred on developing and sustaining relational support for children and young people that provided them with secure foundations. They were focused on setting up systems and relationships that gave children and young people a sense of security that they had people on whom they could rely for support. Within this support framework, supporters focused on working with children and young people to develop skills and resolve problems.

### Providing a loving foundation

Most of the family members stressed the importance of laying a foundation in which children and young people are embedded in family life and feel loved. A number of mothers felt this was particularly necessary for children and young people with disability because they often face additional challenges such as an increased likelihood of experiencing violence and abuse, difficulties in communicating this, and low confidence due to chronic harassment. Mothers described how important it is for children and young people to know they are loved, and the impact when this is absent in their lives.

> You stop being touched in a loving way sometimes when you have a disability. Marcus is big now but I still love scooping him up and carrying him down the hallway to bed … I carry him down, have a chuckle, put him in bed, lie in bed with him – it's important that he is held and he can feel that, he knows that we love him. Just a ruffle on the head, a rub on the shoulder. I think people fear that they will break someone by touching them – I might do something

wrong, they've got a disability, they are fragile. The fear has grown out of the small percentage of the population that do the wrong thing.

*Rebecca, mother of Marcus, aged 8*

For some children and young people with complex support needs, however, the experience of trauma interfered in a fundamental way with how they understood safety and their ability to feel safe. Judith, a long-term foster mother, described the impact of her daughter's experiences in the following way:

> Safety is an almost unachievable goal for Jessica. The last thing she said to me before I left to come here today? She wanted to go out and have some soup with her support worker, and she wanted to know would that be dangerous for her. And that's just horrible, horrible. When she came to me, she [was] just crazy with fear and anxiety, and everything you could think of. She'd been moved around from foster care placement to foster care placement, because the fear and anxiety was coming out in some quite massive behavioural issues. So she was [as] destabilised as you can be, and so frightened.
>
> *Judith, foster mother of Jessica, aged 19*

### Building capability and confidence

Family members all expressed a loving and supportive view of their children. They provided multiple examples of the ways in which they helped develop their sense of capability, confidence and resilience, including through organising more formal support such as therapy, facilitating social relationships, and informally by recognising their efforts.

> When they do something out of the blue we are so on top of telling them how great it was and bringing that to their attention. 'What a great job! That was really good thinking'. Tracey and I try to stay on the same page, I mess up sometimes but if one of us says something even if the other one doesn't agree we stick to it. Our number one priority is the boys, they're number one.
>
> *Olive, grandmother of Jules, aged 11, and Eric, aged 9*

Professionals saw the structured support provided by education and training as foundational in building ability, skills and confidence in children and young people. A number of professionals talked about how difficult it was for children and young people to develop the level of capability and confidence needed to be safe 'without someone looking over their shoulder'. They discussed using role-plays and developmental skill-building approaches across a range of activities, reinforced by pictures and photos, to build capability and confidence.

Two disability support workers saw talking-based, relationship-focused support as particularly valuable in helping children and young people with cognitive disability to navigate social roles because they increase their familiarity with talking about their feelings, make it easier for them to talk about difficult feelings if something negative happens, and increase the likelihood of workers or family members identifying a problem earlier in dialogue.

## Building networks

A number of mothers spoke clearly about the importance of developing a positive and sustainable support network for their children (and the wider family), to build a positive self-concept, confidence and resilience, and thereby increase safety. They talked about underpinning this with actions such as ensuring that children and young people have exposure to disabled and non-disabled children and typical patterns of life, supporting the development of friendships, and helping siblings understand disability from a diversity perspective. For children and young people with complex needs, particularly due to trauma, this was a complex and long-term endeavour, and mothers talked about the web of professionals involved in this, and the constant support and vigilance needed.

> She has been through … all sorts of stuff in her history. So it's so important to say to her, 'How would you like this to be? You'll be safe, we'll look after you'.
> *Judith, foster mother of Jessica, aged 19*

A number of mothers talked about making sure that there was always someone around – family, extended family or trusted neighbours. For two mothers, this extended to a more formal understanding of the need to set up a network of people who love and truly care about the child or young person, to ensure that there were a number of people with their interests at heart actively involved in their lives.

## Putting support in place

Family members described working consistently to put the necessary support in place to ensure their children's safety. One mother, whose son had recently started staying home alone, talked about having good locks and security at home, backed up by known and trusted neighbours. Others talked about using verbal prompts and keeping physical contact with their children to keep them safe when out in public, particularly at risky points such as when crossing roads.

Several parents raised strategies they used to work with schools on safety. Most families had negotiated with schools around providing additional learning support, with several advocating for changing existing systems when their child's needs were not met. This included discussions with schools about focusing more intensively on student safety, especially for students with disability, primarily in response to incidents and concerns involving peer-to-peer harm. Two mentioned working collaboratively with schools on behaviour management plans and programs for their children. A number of families changed their child's school when they found the school unresponsive or inadequately responsive to their concerns about the support being provided and to bullying and violence against their child.

Professionals spoke about how they worked to ensure children's and young people's safety. Some conceptualised this as ensuring quality of care, some as being responsive to what children and young people ask for, and some as making children and young people less vulnerable. For example, a number of disability support services had arranged workshops

for children and young people with external presenters on topics such as cyberbullying, safe spaces, safe sex (for young adults) and safety in the community.

## Focusing on education and communication

Almost all families talked about the value of safety education, but the children's and young people's capabilities very much determined whether this was appropriate or effective. Three mothers noted the importance of finding out the best way to give their children key messages. Some were visual learners, while others needed to learn by experience, and parents had found role-plays and acting out scenarios with humour to be particularly effective.

For children with high and complex communication support needs, both families and professionals believed a formal education process would not be useful or appropriate, and instead tailored individualised processes better suited their needs and developing abilities. Some professionals referred to this as 'teachable moments'. One mother discussed the usefulness of speech therapy to develop communication abilities more generally and the ability to use safety resources in particular. Their family were trying to develop some communication tools for safety and build them into their child's communication system over time to increase their capacity to identify safe and unsafe feelings and convey these to others.

Professionals working in schools, disability support services and therapy services raised the importance of educating children in protective behaviours from a young age and in both the mainstream and special education systems, including emotional regulation and listening to their instincts. Professionals acknowledged that this could be challenging for children with high support needs, who may need touch for reassurance or to be calmed, or be very tactile.

> We use a lot of social stories around using a language that is repetitive and they will remember that. So when we can identify where in the body it feels then this is what you need to say.
> *Nicola, school principal*

Educators in a special school spoke about their decision to introduce a program called SoSafe! for students across the school. This program provides a set of visual and conceptual tools designed to promote social safety for people with 'moderate to severe intellectual disability or autism' (Educational EdICTs, 2015).

Parents saw children and young people who were able to navigate relationships more independently to be in need of a wide range of safety education, including safety in getting around their community, interacting with strangers, dealing with peer pressure and acting on unsafe feelings. Only one mother raised safe sex as an education topic, saying she had spoken about this with her son as he became a teenager. Another mother talked about her concerns for her daughter's sexual safety, but felt she was unable to learn about safety.

Disability support workers said they built safety by identifying where individual children's and young people's gaps in knowledge were, and working from that point to help them develop skills and to modify the environment to increase their safety. One worker pointed

out that this process was not only about developing skills in the child or young person, but also about creating a relationship with them so that they became comfortable enough to share with support workers, or rely on them, when or if they needed help with an issue that concerned their safety. Another talked about the joint responsibility of the community:

> We need to start thinking about it as a community from two different sides: what do staff need to help people be safe and what do young people need to keep themselves safe as possible? If we actually say the words out loud 'what keeps this person safe' or 'what does this person need to be safe' all of a sudden the discussion starts, and you start to look at emotional safety, physical safety, sexual safety … It might mean what we have to do to keep the person safe, what we have to teach the person to help keep them safe, what does the community need to do to provide more safety.
> *India, advocate*

Most families and professionals discussed the concept of stranger danger training. Many felt it was important for children and young people to understand and be able to respond to stranger danger, and families in particular worried a great deal about the risk strangers posed to their children. One person who worked in a support role across multiple schools thought it was essential that stranger awareness training, rather than stranger danger training, was provided to children and young people. She felt that children and young people were unnecessarily fearful of people they did not know, while at the same time lacking awareness of the risks inherent in support relationships.

Professionals suggested training, supervision and ongoing support for staff members as a way of building safety for children and young people. They discussed the potential for short training courses, conferences and in-house training kits to increase disability support workers' knowledge and skills. For example, one disability service was working with university students on placement to develop communication resources about safety for use in training with staff and service users. The small number of participating professionals discussed the potential benefits of diploma-level education and using purpose-designed toolkits. They saw staff education and training as necessary to ensure safety and help workers' prioritise communication, so that children and young people could reliably indicate preferences and problems.

### Managing relationships with staff members

A number of families raised managing relationships with staff members in key institutions as a way they kept their children safe. Across schools, respite and holiday care services, and in-home disability support, mothers talked about the importance of developing and maintaining trusted relationships with staff members. This included clarifying expectations, setting boundaries, forming supportive professional relationships, using staff they knew, and minimising change in the children's and young people's lives.

> [Workers] know immediately 'you're coming into my home, there is a lot of trust there … I need you to respect that it is my home first and it's where you come to work second and the

bucks stop with me'. Lots of clarity and boundaries straight up. I try to be fair and reasonable and clear in what my expectations are.

*Rebecca, mother of Marcus, aged 8*

Like the families, professionals saw consistent staffing, flexibility in approach, clarity, accountability and developing supportive and professional relationships with children and young people and their families as fundamentally important in promoting and maintaining safety. Several thought that workers should be accountable for treating people with dignity, and be removed from their positions if concerns about mistreatment arose.

Professionals saw building stable, long-term relationships between staff members and children and young people and their families as beneficial for children and young people as well as workers. A number of workers recognised the importance of relationships with families, particularly for children who did not use verbal communication. They saw recognising and responding to the concerns of families – and implementing plans to ensure their children's safety – as part of their role.

One mum is very concerned with her daughter even going swimming because there will be boys there. She gets really upset and tells her daughter anything could happen. We try to reassure her about [having] female staff and watching her daughter.

*Kate, disability support worker*

### Taking action on behalf of children

All of the family members involved in the study gave examples of action they had taken to protect their children against harm. They described repeated, in some cases almost constant, engagement with systems to minimise actions that would distress their children, such as complaining about the lack of access to specialist support, lobbying against segregation in mainstream schools, raising bullying and violence against their children with school authorities, and advocating against poor practices in disability and OOHC environments.

As soon as I saw what they'd put her into, I started to lobby for them to get her out of there … They took her out of that class, but it took time. It took meetings with I don't know how many people, and to get a support person for her in the standard class.
*Did that help?*
Yeah. I don't think it made it any easier for her to go, but I don't think it damaged her as much.

*Judith, foster mother of Jessica, aged 19*

Professionals spoke about developing programs and plans for children and young people to learn about safety, individually and in groups, and to be in safe environments. They also discussed their responses to critical incidents involving children and young people, such as being called when someone felt threatened at a bus stop, intervening in peer-to-peer violence at school, and helping children and young people manage anxiety and distress.

## How do you see children and young people risk their personal safety?

Professionals and families both primarily perceived risk in environmental terms, rather than as a responsibility of children and young people themselves – that is, they believed the factors that influenced safety (or lack of safety) often had more to do with elements outside the child's or young person's control than their capacity to learn or implement specific strategies.

Families generally felt that it was difficult for children and young people with cognitive disability to see the possible consequences of their behaviour because there are often two or three steps between their behaviour and the possible outcome. This was at both individual and systemic levels. One mother spoke about her teenage daughter not understanding that she was exposing herself to potential sexual predators by exposing her bra when wiping her face with her shirt. Another talked about the risk of her daughter being removed from her OOHC placement due to severe trauma responses and behavioural problems that arose from attachment disorder, something she felt would compound an already very complex and difficult situation and further damage her daughter's ability to feel safe over time.

Professionals talked about the lack of support services available for families with children who have significant behavioural problems, and how they struggle with little support until they 'get to the end of their tether' and children enter residential care or OOHC. They felt that this prevented a gradual entry into the service system, created trauma in children and young people and their families, and prevented families from focusing on their child's safety because of their increasing struggle. A worker in a disability support service pointed out that, due to privacy legislation, workers know very little about the circumstances of children and young people who are in OOHC. While appreciating their right to privacy, she also questioned the capacity of her service to provide trauma-informed care without having some information about what might best support, or would traumatise, clients.

### Individual qualities of children and young people

Families expressed a high level of concern about the ways in which they felt their children potentially risked their personal safety. Almost all worried about impulsivity and the physical risk-taking that resulted at times (for example, running onto the road or lashing out in frustration). Mothers, particularly mothers of teenagers, worried about their children's lack of capacity to give informed consent.

Professionals also felt that many of the children and young people they worked with lacked awareness of dangers in everyday activities and, without effective and engaged support, this put them at risk. As discussed above, professionals felt it was hard for some children and young people to put their learning into practice, and this made it difficult for them to recognise and respond to potentially abusive situations. Many reported that some young people found it challenging to manage their own strong emotions, control anger and calm down to avoid violence or escalating situations.

### Lack of knowledge

Professionals consistently expressed concern about children's and young people's lack of knowledge about sexuality and what constitutes abuse. Professionals working in both disability support services and school settings were of the view that many families did not explicitly teach their children about safety or what to do if they felt unsafe in terms of building social skills or with regards to sexuality. For example, a disability support worker expressed his concern about the number of young adults who came to his service without a language to describe abuse, neglect or sexuality. In another post-school service, managers commented on the fact that – while young people had been educated about relationships, body image and exploitation at school and again in the disability service – it needed repetition. A number of young people they worked with had an inadequate understanding of what constituted abuse, sex and criminal activity. Educators spoke about the tension in educating teenagers with cognitive disability about sexuality when some families expect their children will never enter intimate relationships.

> I think we don't do justice for some of the students who are graduating and moving on and will go into healthy sexual relationships, because we cannot be as explicit as we would like in our education. I feel as a school we haven't had the opportunity to educate in the way we could, partly because of parent restrictions and partly because of our student requirements.
> *Nicola, school principal*

## Risky social practices and relations

Professionals felt that the fluid and dynamic nature of young people's social relations was difficult for them to navigate. Drinking, using drugs and having unsafe sex were a reality for a number of young people supported by one of the disability services. Support workers felt that changing views among young people about what constitutes sex (including, for example, views that oral or non-penetrative sex does not 'count' as sex), combined with a lack of sex education and conversation about sexuality and safety at home and school left these young people vulnerable to abuse. Social media increased peer pressure for young people in particular. Disability support workers gave examples of young people who had shared images online, not understanding the potential consequences or implications.

Families also talked about how their children's open and generous nature increased the potential for manipulation, peer pressure and being led into negative situations. Both families and professionals conveyed concerns about the willingness of children and young people with higher support needs to trust, and the way in which this trust has been encouraged through necessary reliance on daily support from paid workers.

> … a fair few of them would just listen to any stranger. I think they'd know something isn't right but they have always had support workers there to help them, so if a community member would come up and say 'I'm here to help you' they would trust them because that is what they've had their whole life.
> *Damien, disability support worker*

## What do you do in response to these risks and potential harm?

Families focused on prevention in responding to perceived risks of harm to their children. Professionals also focused on prevention, but within a risk management framework. Both groups reported taking action in multiple instances to stop harm from happening, or from continuing.

### Worrying

Families described feeling extremely anxious about what might happen to their children, and talked at length about their concerns for them. For some, this extended to what they described as a 'hyper-anxiety that something might happen'. These worries included their children getting into a car with a stranger; transitioning to adulthood and 'the freedom and what he will get up to'; other young people developing sexual interest in their child; and a more general fear of 'something happening that I haven't thought of and I can't stop happening'.

Families dealt with these worries by using the strategies outlined below, and also by being involved and engaged in their children's lives. A number of families noted knowing where their children were 'at all times' as important, and several discussed how they drop off and pick up children and young adults when they go out, and make sure their friends' parents do too.

### Focusing on prevention

Some families also had a clear focus on preventing harm from occurring to their child. For some, protecting their daughters meant ensuring they stayed in the special unit at school and were not able to have unsupervised contact with mainstream students, particularly boys. Siblings in some families had a 'watching brief', especially at school, and this was expected to continue into the future. For those with control over funding and support, the power to hire and fire staff was critical in being able to stop disrespectful staff practices. One mother continues to ask what is customary for all the children in the family to help her decide on services and support for her son with high support needs:

> So the school for a time has been trying to encourage me to have Marcus picked up and dropped off by taxi. And I said 'no' and I continue to say 'no'. One, because he is only eight and I wouldn't send my typical child to school in a taxi at eight. Adrian has started catching the bus and I drop him off and wait across the road till he boards the bus, and he can tell me what happens or he can scream for help. I have seen how some of the taxi drivers treat the children [with disability], they pick them up too early, they are sitting outside, the school doesn't open for 15 minutes, and it's freezing cold winter, and it's not okay.
> *Rebecca, mother of Marcus, aged 8*

Disability support workers' views were consistent with this, with three noting that they frequently framed safety messages to children and young people in the context of what was expected for all community members, not just those with disability.

> I think that very often we can and should take the disability and put it on one side and go: 'This is what you need to do to keep yourself safe. Everybody in society needs to do this!'
> *Fiona, disability services manager*

Professionals focused on providing education to children and young people so that they were better able to understand safety and seek help. They reported that communication, information and education needs to be clear, explicit and not rely on assumed knowledge. Disability support workers described the need to do lot of groundwork and preparation, the importance of taking small steps over time and experiencing some resistance from families, especially regarding education around sexuality. They discussed the critical need to make communication symbols and systems about safety, harm and relationships available to children and young people. A therapist also noted the importance of involving the whole family in learning the child's or young person's communication system as, in their experience, siblings were often the ones who alerted families to harm.

## Managing risk

Families talked about the ways they minimised the risk of their children experiencing harm. Ensuring a safe physical environment, using education strategies to build children's and young people's skills, and developing trusting relationships with staff members have all been mentioned earlier in this section, and families also saw these strategies as ways to reduce risk. Most frequently, families acknowledged that while, as a parent, they wanted to avoid all risk, they understood they couldn't, and that some risk was inevitable. They hoped to manage risks so that their children's life experiences were closer to those of children and young people without disability.

One family that managed its funding took an explicit approach to risk management in employing staff members; providing a manual about communication and household safety issues; and working closely with staff members for months before leaving them alone with the child. This mother found it both time-consuming and draining, but thought it was essential for her to feel safe leaving him alone with staff members. Despite having checklists and manuals, she commented that there was a degree of faith and trust involved. Other families had ideas for using technology to better recognise and manage risk where children and young people were unable to talk about what had happened or might happen, such as a headband that measured stress and wrist alerts that would send an alert when they moved beyond a certain radius from home.

Almost all professionals stressed the need for effective institutional-level management of risk for children with high and complex support needs, saying 'you can't empower them to protect themselves'. They saw the need for systems that trusted children and young people, responded based on what they said, acted quickly without first seeking secondary verification of harm, minimised bureaucracy (especially for initial responses), and made sure children and young people received a response of 'right, fine – I'll be right there', rather than 'what, where, when?'.

Professionals also stressed the need for relationship-based policies and procedures to better manage risk and to prevent and respond to harm in children's and young people's lives.

While acknowledging that criminal record checks and Working with Children Checks focus on keeping children and young people safe, disability support workers in particular noted their limitations, saying that they don't take account of individual preferences for relationships that are personally empowering for children and young people. This is a particularly active discussion in the context of the emerging NDIS, which has significant potential to facilitate more personalised support relationships between children and young people with disability and support workers.

## Taking action

All families talked about making complaints and taking action on behalf of their children where they had experienced individual and systemic actions that caused distress and harm. School was the most common institution where children and young people had experienced harm, and parents talked most commonly about the peer-to-peer abuse they experienced and poor systemic responses to it. All worked with staff members in the schools to resolve problems, but two families had moved their children to new schools when problems became insurmountable (two other young people also spoke retrospectively about moving school).

> Mainstream was really bad. Eric was in the support unit there and Jules in mainstream but it wasn't working. He was being thrown on the ground, stood over, stomped on and kicked. There was one incident where he got pushed over on the ground and kids circled him, they were just walking over the top of him.
> *How did the school deal with that?*
> The principal got involved, they were thinking about suspending them but decided not to because there was 11 of them so they ended up giving them three-day detention.
> *Tracey, mother of Eric, aged 9, and Jules, aged 11*

A number of families spoke about systemic actions that had significant negative impacts on children. This included rigidity in applying policies, lack of access to necessary services, lack of recognition of systemic abuse and lack of interest in the complaints made by children and young people and their families. For example, one family's experience of the OOHC system included making multiple complaints to the relevant ministers and ombudsman (and about the ombudsman) about the lack of therapy support offered, the system's failure to provide essential support and aids, the lack of access to education in a mainstream setting, and the lack of consultation and appropriate planning for transitioning out of OOHC. In this context, a transition meeting was held with no notice and no support people in a location the child had requested the department not to come to – her school.

> So, because I was being so fierce in my arguments for her to have what she needed, they moved in on her alone, without me, and made her – she tells me they made her tell them which one of those four therapies she would like to keep. Extremely manipulative. She actually said two. She actually felt quite proud of herself for living through that scenario, and for being able to say two of them... And these are people that you should be able to trust.
> *Judith, foster mother of Jessica, aged 19*

The professionals contributing to this study were all very supportive of families and children and young people who took action to resolve or redress harm. However, an advocate noted the impact of this on families in saying:

> A lot of parents get the reputation of being the nightmare parent but they are advocating so much for their child to live a full, productive, dignified life, you have to make noise to get that… We need those parents, and it's wrong they have to fight so hard for such a simple thing as a dignified life and to have their child kept safe.

Disability support workers provided a number of examples in which they helped children and young people seek information and make complaints. For example, a young woman who was sexually harassed at a pub was supported by a disability service in making a complaint against the venue. School staff members spoke about how they worked collaboratively with families to resolve issues of concern and identify possible problems when children and young people were unable to share information:

> With our non-verbal [students] we are always looking for behaviour change, and we have noted certain behaviour changes mean certain things and what the triggers are. And what we find for those students is there will be a behaviour change and we haven't seen a trigger, there is nothing we can link it to. They are the behaviour changes we want to note and communicate to the parents because any change in behaviour means there is something happening. And it may be as simple as pain but we don't know that.
> *Nicola, school principal*

## How well do you think systems recognise children's and young people's perspectives of safety?

Families were not confident that systems recognised children's and young people's safety needs. Where they felt more confident, this was linked to established relationships of trust with staff members and management (as detailed above).

### High numbers of staff children do not know

Several families felt the safety messages they tried to teach their children were compromised by the service models used in disability support, leisure and holiday care services, which often rely heavily on casual or short-term staff.

> On the one hand you are telling them not to talk to strangers and then here you are saying 'you need to go off with this stranger now' or you take them to a group [through disability support service] … and you don't know which worker is going to be on which day. So you are like 'don't talk to strangers' but I am going to leave you with this bunch of strangers!
> *Tracey, mother of Jules, aged 11, and Eric, aged 9*

Families also felt that children and young people with high and complex support needs who were unable to speak were particularly vulnerable using taxis, where there were no witnesses.

Professionals agreed with this view, expressing that children and young people, particularly those with high and complex support needs, are put at risk when they are taught to trust anyone, and by having a high number of strangers in their lives. Disability support workers pointed to the trend towards casual staffing, noting that this will likely increase with the NDIS, and potentially increase risk. They also raised concerns about the increased likelihood in a highly casualised work environment for workers to lack the training, skills and capacity to understand there is a problem and respond appropriately.

### Needs poorly met in schools

Families spoke at length about tensions and difficulties for students across educational systems. For students in mainstream schools, families consistently spoke about isolation, loneliness and the lack of effective responses to peer-to-peer abuse. Across both mainstream and special school settings, families discussed the low expectations of students with disability at a systemic level, which they felt created a climate of disrespect that made it easier for harm to occur. Disability support workers who worked in both school sectors felt that the school curriculum is so focused on academic skills (mainstream education) and life skills (special education) that little attention is given to interpersonal skill-building, which is very important for children to whom it doesn't come naturally. Educators spoke about how schools are strongly influenced by risk management and legalistic approaches, which impact on creativity:

> I think we are absolutely bound by risk here. The amount of fear from a school's perspective now if something goes wrong and we are not covered. We are constantly aware of the legalities and I think that has changed a lot of what we feel we are able to do in a school setting. And we hear the stories of, you know, back in the 80s or 90s this and this was possible. I know now that there is so much more legislation around that some of those things you could work on then are not possible in the same way, like sexuality issues.
> *Nicola, school principal*

### Lack of focus on disability support needs

Families with experience of the OOHC system in particular pointed to a constellation of serious systemic issues, including the inadequate assessment of children and young people with disability, lack of therapy support, inability to choose schooling that would keep children and young people safe, and inadequate support for disability-related needs.

### Risk orientation

Staff members felt that disability support, respite and vacation care services were still very bureaucratic, risk-oriented, document-focused and not geared towards educating children and young people with disability. Despite this, several could see positive changes occurring. One professional talked about taking 'calculated risks' rather than 'wrapping' people up, so that they could develop more skills and experience in their leisure and disability support

activities. Another could see that crisis responses were improving over time, and felt that their service was becoming more focused on the person and less on the paperwork.

# 3  Main conclusions

**Key points**

- **Systemic impacts on children's and young people's lives need to be addressed.** The effects of systemic limitations and failures, segregation, lack of choice and discrimination were evident in the research findings. These findings showed that children and young people with cognitive disability have very different living patterns to their peers without disability. They were vulnerable due to the multiple ways in which institutional practices acted to isolate them from local communities and long-term support relationships. Action needs to be taken on multiple levels to resolve the fact that children and young people with disability are living their lives very differently to other children and, as a result, are exposed to significant risk.

- **Work is needed to assist children and young people and their supporters to recognise and assess the relative risk of harm.** This study's findings, together with related literature, indicate that while some children and young people with high support needs are unable to protect themselves against harm, many others have or can develop basic self-protection skills but find it very difficult to identify or understand more systemic risks or to avoid or respond to more insidious abuse. For example, several children and young people expressed a sense of personal responsibility for keeping themselves safe, and did this by making themselves less visible to avoid attracting attention. This may help them avoid harassment, but it also increases the risk of predatory abuse. A risk management focus may act to 'put a lid' on concerns around safety and harm, rather than create new relational solutions for children and young people who require sustained involvement with trusted adults to feel and be safe and to express this.

- In most cases, the emphasis that children and young people and those who support them placed on stranger danger did not take into account the difficulty of calculating risk when meeting new people or acknowledge that a high proportion of children and young people with cognitive disability are abused by those they already know, particularly peers. While several children and young people talked about times when it was clear that they, or situations around them, were not safe (such as being physically injured or bullied), it was much more difficult for them to articulate uncertainty or disquiet, particularly about people in authority. The implications of this are twofold:

  o Many children and young people lack the skills and support to identify and act on feelings and instincts that could keep them safer from potential abuse in institutional settings.

  o A diminution of the social life of children and young people as they grow and develop, as a number indicated that they generally feared people they did not know (for example, people standing at the bus stop).

- **The nature and quality of support relationships need to be monitored in a strategic and concerted way.** Children and young people and their supporters placed a high priority on relational support to protect them against harm across multiple institutional settings. This is required at individual and systemic levels because relationships feature centrally in current and forthcoming large-scale policy developments. This study (and others) showed that the reliance children and young people have to place on relationships with staff members at an individual level is a source of tension and concern, due to their lack of knowledge and education about abuse and their limited capacity to act on concerns. At a systemic level, high staff turnover, lack of training and skill in workers and managers, and increased trends towards casual staffing all point towards increasing risk.

- **Evidence-based educational resources and strategies are needed to improve children's and young people's capacity to identify and respond to potential harm.** Such resources also need to include initiatives for professionals and families, to ensure children and young people are effectively supported if they disclose harm, and that harm is recognised and responded to if they do not use spoken language and instead provide indications of harm through behaviour or other indirect means. This extends to education about sexuality and social relationships. These resources and strategies will support efforts to decrease the high rates of harm; increase the skills of children and young people and their supporters; and help children and young people identify and act on feelings and instincts, which could keep them safer from potential abuse in institutional settings.

- **Active participation of children and young people with disability needs to be developed and supported in a number of domains.** The range and diversity of the children and young people with significant support needs who participated in this study demonstrates that it is possible to have safe, creative conversations about sensitive topics in their lives. More than a matter of good practice, this is also a requirement under both the United Nations' Convention on the Rights of the Child and Convention on the Rights of Persons with Disabilities. Tailored, innovative methods for effectively listening and responding to the diverse views and perspectives of children and young people with cognitive disability need to be encouraged, to ensure they can contribute to their personal circumstances, service environments and broader policy change.

There are marked similarities between the findings of this study and the ACU *Having a Say* study, including the importance of having reliable, safe and trusted adults in children's and young people's lives, and the foundational nature of home in building resilience and confidence. Where differences are evident between the two studies, they are important because they are generally linked to systemic disadvantage. Differences included the way in which some children and young people with disability equated feeling safe with being safe; additional barriers to being able to implement safety strategies; less effective responses to feeling intimidated and threatened; and a more frequent lived experience of abuse.

This final section of the report draws the findings together, and discusses how the data sheds light on a number of critical safety issues concerning children and young people with cognitive disability. It also discusses how the findings relate to both the ACU study to which it is linked, and to the existing literature on the safety and abuse of children and young people with disability. A number of these findings highlight how conversations with children and young people with cognitive disability need to be approached to access deeper issues and concerns that are rarely discussed and not readily identified. This leads the research team to outline a number of conclusions and areas for action.

Children and young people in this study provided a detailed picture of what being safe meant to them. They focused on both physical and relational safety, linked to keeping away from physical risks (such as staying off the road or keeping the door locked at night) and feeling safe in their relationships. They emphasised the importance of feeling safe and secure, having access to help from trusted adults, not being at risk of harm from known and unknown people, and having strategies and the opportunity to put them into practice.

Children and young people described a series of factors that helped them to feel and be safe. These included having a secure foundational space (home), feeling known and valued, having someone to confide in, not being exposed to strangers and having appropriate opportunities to learn about how to be safe (both formal and informal). Things that made it difficult for children and young people to feel and be safe included fears and worries about their safety, feeling out of control in situations, the impact of having experienced abuse of various forms, peer pressure, being under-supported through transitions and complexity in their family lives.

Families and professionals all viewed the children's and young people's understanding of safety as limited. They shared concerns about the children's and young people's lack of safety or self-protection skills, which put them at risk of harm. In some cases, they felt that children and young people (especially those with very high support needs) were not able to take any action at all around safety, and questioned whether they had any awareness of safety concepts or, in some cases, a language for expressing concerns about safety. They also believed service systems operated in ways that made it difficult for children and young people to identify safe and unsafe people in their lives – for instance, by requiring them to rely on a large number of casual staff.

Supporters talked about the actions children and young people took, but also about strategies of avoidance and resistance they more often saw, which they felt arose from anxiety and trauma. They responded to this by building and sustaining relational support for children and young people that provided them with secure foundations. Within this support framework, families and professionals took a parallel focus on developing skills in children and young people, and resolving problems.

Families focused on prevention in responding to perceived risks of harm to their children. Professionals also focused on prevention, but within a risk management framework. Both groups reported taking action in multiple instances to stop harm from happening or continuing. Neither group were confident that institutions recognised children's and young people's safety needs. Where they felt more confident, this was linked to established

relationships of trust with between families and institutional staff members and management.

## Comparison with ACU's *Having a Say* study

It is clear in analysing the two research reports that there are marked similarities in findings, suggesting that cognitive disability is not the defining feature of children and young people. However, the impacts of impairment (physical and intellectual) and disability (social and environmental) are significant in the lives of children and young people like those involved in the study. Where differences are evident between the two studies, these are important because they are generally linked to systemic disadvantage.

The relational nature of safety was clearly evident in both studies, with children and young people reporting the importance of having reliable, safe and trusted adults in their lives, and of having adults who were receptive and really listened to them. The fundamental importance of home and the role that it plays in establishing and maintaining children's and young people's confidence, wellbeing and resilience was also a strong theme in both this study and the ACU safety study. Findings from both studies highlighted that home was the safest place for most children and young people.

A number of children and young people in the current study equated being safe with feeling safe and secure, with regard to both places and people. This differs from the ACU study, which found that children and young people made a distinction between feeling and being safe, and that you could be one without necessarily being the other.

While many of the safety strategies children and young people drew on were similar to those reported in the ACU study, differences emerged in the degree to which they felt and were able to use their strategies, and the importance they placed on this. Children and young people with cognitive disability faced a number of additional barriers to implementing strategies, including a lack of control within institutional settings, limited numbers of receptive adults, limited opportunities to practise using strategies, and the impacts of impairment (on communication, understanding and anxiety, for example).

A further distinction between the two studies was evident in the responses of children and young people with cognitive disability to feeling threatened and intimidated. While a small number of children and young people talked about help-seeking strategies, they more commonly reported using strategies of avoidance and resistance. These strategies were mostly linked to stress and distress, limitations in what they could manage due to their functional impairments (for example, cognitive impairments or anxiety or post-traumatic stress disorders), and a sense of personal responsibility for minimising potential harm by reducing their visibility (for example, by dressing in a non-descript way). This differs from the responses of children and young people in the ACU study, which centred more on institutions' responsibilities for protecting them against risk from strangers, and helping them to feel and be safe.

Many children and young people with cognitive disability talked about how they understood being safe as the absence of threat and harm from their lives. While this is in part consistent

with the results of the ACU study, which also found absence of harm to be a theme, it differs somewhat in emphasis, as children and young people who were able to articulate the experience talked almost universally about having experienced harm. It is particularly concerning that the ACU study found that children and young people who had experienced harm reported more reluctance to trust adults or deem them to be safe than children and young people who had been protected or who had successfully navigated the threat. While a number of the participants in the current study were unable to articulate this concept, they had certainly experienced significant levels of harm.

## Conclusions

A number of key issues important to children and young people, policy and practice can be drawn from the study findings. In each case, the critical issues identified by children and young people and their supporters were consistent with the existing literature on abuse and safety for children and people with cognitive disability. These include the need to counter the systemic impacts of harm in these children's and young people's lives; the need to assist children and young people and their supporters to recognise and assess the relative risk of harm; the importance of relational support in preventing abuse; the need for evidence-based education; and the need to support and promote the participation of children and young people with cognitive disability in a number of domains, including in daily living activities and in informing policy change.

### Systemic impacts on children's and young people's lives need to be addressed

The effects of systemic limitations and failures, segregation, lack of choice and discrimination were evident in the research findings. For example, children and young people in schools, vacation care and disability services were exposed to large and shifting workforces of casual and short-term support staff, and had to rely on staff members they did not know for sometimes intimate personal care. Children and young people with communication impairments either did not have systems in place that support workers used, or the systems were inadequately shared with all staff members due to the changing nature of the workforce. A number of children with high and complex needs needed to leave their local community in order to access the classes or schools their families felt best met their needs.

These findings showed that children and young people with cognitive disability had very different living patterns to their peers without disability. They were vulnerable due to the multiple ways institutional practices acted to isolate them from local communities and long-term support relationships. Families and professionals were concerned about how children's and young people's sense of public and private, safe and unsafe was formed and shaped in this context, saying that their 'trust radars were broken'. This is consistent with research with young people with physical disability, who have spoken about becoming 'immunised' from regarding their body as their own domain due to multiple handling experiences every day of their lives, and the impact of this on their understanding of their own bodily integrity (Hollomotz, 2011).

## Work is needed to assist children and young people and those who support them to recognise and assess the relative risk of harm

This study's findings, together with related literature, indicate that while some children and young people with high support needs are unable to protect themselves against harm, many others have or can develop basic self-protection skills and capabilities but find it very difficult to identify or understand more systemic risks or to avoid or respond to more insidious abuse (Briggs and Hawkins, 2005; Higgins and Swain, 2010; Murphy et al., 2007). For example, several children and young people expressed a sense of personal responsibility for keeping themselves safe, and did this by making themselves less visible to avoid attracting attention. This may help them avoid harassment, but it also increases the risk of predatory abuse. A risk management focus may act to 'put a lid' on concerns around safety and harm, rather than create new relational solutions for children and young people who require sustained involvement with trusted adults to feel and be safe and to express this (French et al., 2012; Robinson & Chenoweth, 2011).

In most cases, the emphasis that children and young people and those who support them placed on stranger danger did not take into account the difficulty of calculating risk when meeting new people or acknowledge that a high proportion of children and young people with cognitive disability are abused by those they already know (Stalker & McArthur, 2012; Grossman & Bensy, 2008). While several children and young people talked about times when it was clear that they, or situations around them, were not safe (such as being physically injured or bullied), it was much more difficult for them to articulate uncertainty or disquiet, particularly about people in authority. The implications of this are twofold:

- Many children and young people lack the skills and support to identify and act on feelings and instincts that could keep them safer from potential abuse in institutional settings. For children and young people with high and complex support needs, this extended to the lack of a language to express feelings, concerns or experiences about safety or harm.

- A diminution of the social life of children and young people as they grow and develop, as a number indicated that they generally feared people they did not know (for example, people standing at the bus stop).

A number of researchers raise the need to build capacity to resist maltreatment at multiple levels – in individuals, within organisations, at the community level and at a broader societal level (Marsland et al., 2007; Stalker & McArthur, 2012). When resources, attention and energy are focused on prevention at the whole community level, several studies argue there are benefits for all children and young people with disability, as well as improved responses to those who experience harm (Briggs, 2006; Murray, 2004; Mepham, 2010).

Movements and initiatives such as inclusive schooling and individualised disability funding and support represent a paradigm shift towards less organisationally oriented and more inclusive lives for people with disability. For children and young people with cognitive disability to feel and be safe in these changing environments, a developmental approach to safeguarding is required. Such approaches can build children's and young people's confidence and capabilities to recognise and act on their instincts to the best of their

abilities, learn strategies tailored to their strengths and needs, and develop mutually trusting relationships that enable harm to be disclosed and acted on. Connected to this is the response of those trusted adults, who need to be equipped with the resources and skills to take action to prevent and respond to children's and young people's concerns.

Careful work is also needed in this space to better understand how children and young people might combine and prioritise risk in situations where they identify people as safe who have been identified through other mechanisms as posing a risk to them – for example, the OOHC system (Higgins et al., 2007).

## The nature and quality of support relationships need to be monitored in a strategic and concerted way

Almost all children and young people articulated the importance of support that was grounded in being known, valued and cared for – either verbally, through their maps or through observed behaviour. This extended across domains, including peer relationships, family relationships and institutional relationships with staff members. This finding is consistent with a well-established body of research about safeguarding for people with disability (Mepham, 2010; Murray, 2004; Robinson, 2012; Stalker & Connors, 2012) and about children's participation in their lives and institutions they use more broadly (Graham & Fitzgerald, 2011; Kellett, 2011). Families in this study focused on developing relationships, reducing social and physical isolation, and building strong and ongoing formal and informal networks for children and their family across multiple domains, which was also a feature of the safeguarding literature. Emerging research with children and young people with cognitive disability about safety in school also notes the importance they place on being listened to, having their capabilities recognised and being believed (Robinson & McGovern, 2014).

Minimising the disruption in children's and young people's relationships and supporting their growth and development may increase their likelihood of feeling able to disclose harm, and increase protection against harm across multiple institutions. Against the primary finding of home and family as a safe and trusted place, it is, however, important to note the complex and sometimes difficult nature of family relationships, which some children and young people raised in this study

This central finding around the importance of relationships is not new or novel. However, while it may seem self-evident, the nature and quality of support relationships need to be monitored in a strategic and concerted way because these feature centrally in current and forthcoming large-scale policy developments such as the NDIS. In the future, care – which is currently service-oriented – will be provided in much more devolved and individualised environments, increasing the importance of identifying supportive practice and intervening in problematic relationships. The NDIS offers significant opportunities for the development of meaningful relational support. However, one of the biggest risks is the high number of strangers or new people in the lives of children and young people with disability, and the tensions that arise between needing to trust people who are there to support them and the risk this poses. This study (and others) showed that the reliance children and young people have to place on relationships with staff members at an individual level is a source of tension and concern, due to their lack of knowledge and education about abuse and their

limited capacity to act on concerns. At a systemic level, high staff turnover, lack of training and skill in workers and managers, and increased trends towards casual staffing all point towards increasing risk.

## Evidence-based education is needed

The known high levels of abuse and neglect in children's and young people's lives (Jones et al. 2012; Sullivan & Knutson, 2000) appear to be reflected in this study. While we did not ask children and young people about their experience of harm, almost all who were able to articulate it told us about interpersonal violence, abuse and harassment they found significant.

In this study, professionals expressed concern about families' resistance to children and young people learning about abuse, sexuality and personal relationships. They also perceived a lack of consistency in teaching these concepts to children and young people, and a lack of robust, evidence-based programs to support authentic learning in this area. They felt that this resulted in children and young people lacking a language to express abuse, sexuality and body parts, and in a lack of communication resources for children who use little or no speech. Such findings are consistent with earlier research that found many parents were unsure about when and how to deliver messages about abuse prevention to their children, feeling confident about delivering stranger danger messages but much less so about conveying crucial messages such as those around inappropriate touching from personal care providers (Hunt & Walsh, 2011).

The existing literature is clear on the value of education and training for both young people with disability and those who support them as an essential component of preventing and responding to abuse (Briggs, 2006; Coulson Barr, 2012; French et al., 2009; Khemka et al., 2009). A recent audit of sexual abuse prevention policy and curriculum guidelines in primary schools (Walsh, Brandon & Kruck, 2015) found that, while they contained overarching statements or guiding principles about inclusivity and respect for diversity, little detail was included to assist teachers in differentiating the curriculum to meet the learning needs of groups of children who may have an increased risk of abuse, including children with disability.

Any educative response therefore needs to acknowledge the diverse nature and range of abilities of children and young people with cognitive disability, and be grounded in care, respect and valuing their different knowledge, experience and abilities. It is critical for children and young people with disability that evidence about the best methods to maximise and support learning underpins any education, and that those delivering programs to children and young people with high support needs are trained and supported to do so.

Children and young people and their supporters need information about and ready access to well-evaluated programs. A small number of evidence-based resources are emerging in this space, such as the SoSafe! training framework (Educational EdICTs, 2015). This program comprises a set of visual and conceptual tools designed to promote social safety for people with high support needs due to cognitive disability, using a standardised framework of concepts, symbols and visual lesson materials. The Safe4Kids program is delivered through schools with a primary focus on teaching students a range of strategies to help keep them

safe. Emphasis is placed on developing a language and culture of safety for both children and adults by improving communication between them and by broadening the networks available to children when they feel unsafe. A whole-of-community approach is taken, and the program includes modules for school staff, families, and local agencies and community groups (safe4kids.com.au, 2015).

Adults who work with children and young people with high support needs, and families, also need education on preventing abuse and promoting personal safety, grounded in the same principles of relational support as education for children and young people. Notwithstanding the importance of education and ongoing support for children and young people to develop and thrive, it is a reality that many children and young people with cognitive disability and high support needs will continue to rely on the adults around them in part or in full for support and protection.

In addition to drawing from educational and children's domains, research with adults with disability about their experiences of abuse may provide a rich source of evidence from which to develop training and educational materials for children and young people with disability. Engaging with Disabled People's Organisations to develop programs and approaches may support a grounded, grass-roots approach to education.

## Active participation of children and young people with disability needs to be developed and supported in a number of domains

It is necessary to continuing pursuing ethical ways to have conversations with children and young people with cognitive disability about safety and harm in private, institutional, policy and research settings. This is the case for all children and young people, as highlighted in the ACU study, but the need is amplified here because children and young people with cognitive disability are so often excluded from participation. Previous research also highlights the dangers of dominant normative understandings of children, and of child sexual abuse, excluding children and young people with disability or including them only partially in broader initiatives about preventing and countering abuse (Briggs & Hawkins, 2005; Dyer & Teggart, 2007; Goodley & Runswick-Cole, 2011).

This study has demonstrated the value of research that allows conversations with children and young people in multiple ways. While not without challenges and limitations, this approach is needed to ensure these distinct voices are heard. There is a clear need for further research that considers the methods' strengths and limitations; the topic's sensitive nature; and the inherent tensions in balancing multiple views and perspectives, some much more articulate than others. Further investigation of the factors that support children and young people with cognitive disability who have strong affiliations with mainstream institutions and protective relationships with people in those institutions would be very valuable. Exploration of the disconnections and loss of relationships that occur during transitions and changes in children's and young people's lives – particularly system-driven transitions such as moving from primary school to high school or leaving OOHC – would be similarly valuable.

A number of key social policies affecting children and young people with disability are underpinned by principles of community engagement and informal network development

which build from local and personal connections. A national safeguarding and quality framework for the NDIS is currently being developed at a federal level. Similarly, the Third Action Plan for the National Framework for Protecting Australia's Children is in development. The degree to which the perspectives of children and young people with cognitive disability have informed these policies or other core policies such as the National Safe Schools Framework is unknown but likely to be limited.

This research also highlights the importance of effectively acknowledging and responding to the diversity of people with cognitive disability in policies and practice. All the children and young people in this study had significant but quite different needs for support and education. The wide range of interests, preferences, skills and needs found in this small sample of 22 young people represents a small fraction of the diversity of people with cognitive disability. Multiple strategies are needed to meet children's and young people's safety needs, ranging from those who are highly dependent on others for communication and all daily living activities, through to those who have informed intimate relationships, who face a completely different set of opportunities and risks. Trauma-informed strategies are needed to respond appropriately to the known high levels of harm experienced by children and young people with disability.

A certain tension emerges through the findings of this study, in that the factors children and young people said helped them to feel and be safe do not necessarily centre on institutions. Children and young people are calling for stronger, deeper relationships that they can rely on to help them safely navigate a range of institutional settings and the people they encounter in them. The intersections and interactions between public and private spaces – between home (with its foundational role for most in sustaining, nurturing and building), friendships and institutions – are intimately bound together for children and young people who can't independently navigate their own lives.

> *What made you feel safe that day?*
> Knowing that if I needed help, I yell out 'Mummy!' and she'd come.
> *Jules, aged 11*

# Appendices

# Appendix A: Glossary

| Term | Definition |
|---|---|
| ACU | Australian Catholic University |
| Children | People aged under 12 |
| Young people | People aged between 12 and 25<br><br>For young people with disability, it can be appropriate to consider age more flexibly due to the barriers to achieving milestones and reduced opportunities for young adult experiences (Kellett, 2011; Hopkins, 2010). |
| Cognitive disability | Children and young people with intellectual disability, acquired brain injury, mental illness, specific learning disabilities and neurological conditions, and those on the autism spectrum. Cognitive impairment can be present when a child is born, or be acquired later in life. It can decrease children's and young people's capacity to concentrate, remember, react to emotions, formulate ideas, solve problems and reason (Gray, Forell & Clarke, 2009). |
| Disability | This research drew from the interactional understanding of disability (Shakespeare, 2014), which understands the experience of disability as a holistic one where the effect of impairment is acknowledged along with social and systemic factors, which together encompass the experience of disability. |
| CCYP | Centre for Children and Young People |
| NDIS | National Disability Insurance Scheme |
| NDS | National Disability Strategy |
| OOHC | Out-of-home care |
| SCU | Southern Cross University |
|  |  |

# Appendix B: Disclosure of harm

Experience of victimisation was not the subject of this study; however, more than half of the children and young people in this study disclosed harm previously experienced in institutional contexts, including bullying, peer-to-peer abuse and violence; victimisation because of their impairment; and sexual harassment and assault. After making appropriate checks, the research team were assured that none of these disclosures of abuse, bullying or victimisation pertained to a current or recent experience; all were historical, had been previously disclosed and had been reported to the appropriate authorities. The research team was not required to make any reports of abuse, bullying or victimisation to authorities. The process by which the research team was assured that no reports were required is detailed below.

Where experiences of abuse, victimisation or bullying were disclosed, the research team followed a clear process, using a disclosure protocol developed at the outset of the project designed to ensure the immediate safety of the children and young people and that they were not further traumatised by their participation in the research. The protocol was guided by the ethical requirements of ACU's and SCU's human research ethics committees, which approved the research.

Children and young people were not pressed for further detail of the harm, beyond seeking sufficient detail to ensure that they were not in immediate danger, and that they had received support from another person in addressing the harm. Researchers determined whether children and young people were at current risk of harm (for example, whether they were still involved with the institution where the harm took place). With the consent of children and young people, informal support people (professionals and family) were asked about the support provided to them, and their level of safety from further harm. The research team took this course of action where concerns arose around participants' capacity to understand and act on their own safety. All children and young people who disclosed harm provided consent for the research team to speak with informal support people.

The two young people who disclosed sexual harassment and assault were well supported and already dealing, or had dealt, with the issues through appropriate avenues, including criminal justice and counselling agencies. The research team determined that it was not necessary to make any reports to child protection or justice agencies, as they were aware of these matters.

In addition to the general safety strategies and risk management processes included through university ethics approval, the heightened risk of abuse experienced by children and young people with disability was acknowledged and addressed in the project methodology in the following ways:

- For children and young people with increased vulnerability (due to lack of functional communication, challenging behaviour, exclusion from services, isolation and so on), particular effort was made to recruit supporters from two life domains to the study.

The aim here was to mediate the impact of support being provided by a potentially dominating supporter, should they wish to discuss discomfort about practices or disclose abuse. Fewer supporters were recruited for interviews than expected, although informal discussions were held with service providers and family members supporting all children and young people during the recruitment and planning phase of the research.

- The interview series was managed wherever possible so that the children's and young people's reliance on supporters was minimised, through the use of trained researchers, modified research tools and repeat informal interviews. Where possible, interviews with children and young people were conducted without the presence of supporters, or with supporters involved in only part of the interview.

- Supporters were provided with guidance about their role as supporters, rather than participants, in the interviews. This approach has been used successfully in previous work with staff members of institutions and large facilities for people with cognitive disability.

- Participants in the study were provided with an information package that included contact information for services that children and young people with disability could easily access – People with Disability Australia (PWDA), Children with Disability Australia, Kids Helpline and Communication Rights Australia. The research team made warm referral to partner PWDA through the project sites for information and education as well as advocacy.

- Direct disclosures of abuse were addressed using the disclosure protocol. Non-direct disclosures were addressed by exploring with further questions, if possible, if the issue raised did not concern a supporter present in the room with them. In some instances, children and young people with high support needs were only able to provide limited detail. Where children and young people indicated distress or discomfort, the protocol for follow-up action included strategies to further explore possible abuse as the cause and take appropriate action, including:
  - reporting the abuse to the relevant authorities (such as police and child protection)
  - holding discussions with the most appropriate supporter (preferably in a domain not connected to the issue raised)
  - warm referral to PWDA for advocacy support if appropriate and desired.

# Appendix C: References

Aarons, N. M., Powell, M. B. & Browne, J. (2004). Police perceptions of interviews involving children with intellectual disabilities: a qualitative inquiry. *Policing and Society*, 14, 3, 269–278.

Akbas, S., Ahmet Turla, A., Karabekiroğlu, K., Pazvantoğlu, O., Keskin, T. & Bo¨ke, O. (2009). Characteristics of sexual abuse in a sample of Turkish children with and without mental retardation, referred for legal appraisal of the psychological repercussions. *Sexuality and Disability*, 27, 205–213.

Alriksson-Schmidt, A. I., Armour, B. S. & Thibadeau, J. K. (2010). Are adolescent girls with a physical disability at increased risk for sexual violence? *The Journal of School Health*, 80, 7, 361–367.

Astill, F., Bratel, J. & Johnston, C. (1999). Giving children a voice: the challenge of disability. In J. Breckenridge & L. Laing (eds), *Challenging silence: innovative responses to sexual and domestic violence*. St Leonards, NSW: Allen & Unwin.

Baladerian, N. J. (1991). Sexual abuse of people with developmental disabilities. *Sexuality and Disability*, 9, 4, 323–335.

Baldry, E., Bratel, J. & Breckenridge, J. (2006). Domestic violence and children with disabilities: working towards enhancing social work practice. *Australian Social Work*, 59, 2, 185–197.

Botash, A. S., Babuts, D., Mitchell, N., O'Hara, M., Lynch, L. & Manuel, J. (1994). Evaluations of children who have disclosed sexual abuse via facilitated communication. *Archives of Pediatrics & Adolescent Medicine*, 148, 12, 1282–1287.

Boxall, K. & Ralph, S. (2010). Research ethics committees and the benefits of involving people with profound and multiple learning disabilities in research. *British Journal of Learning Disabilities*, 39, 173–180.

Briggs, F. (2006). Safety issues in the lives of children with learning disabilities. *Social Policy Journal of New Zealand,* 29, 43–59.

Briggs, F. & Hawkins, R. (2005). Personal safety issues in the lives of children with learning disabilities. *Children Australia*, 30, 2, 19–27.

Brownlie, E. B., Jabbar, A., Beitchman, J., Vida, R. & Atkinson, L. (2007). Language Impairment and Sexual Assault of Girls and Women: Findings from a community sample. *Journal of Abnormal Child Psychology*, 35, 4, 618–626.

Bruder, C. & Kroese, B. S. (2005). The efficacy of interventions designed to prevent and protect people with intellectual disabilities from sexual abuse: a review of the literature. *Journal of Adult Protection*, 7, 2, 13–27.

Brunnberg, E., Bostrom, M. L. & Berglund, M. (2012). Sexual force at sexual debut. Swedish adolescents with disabilities at higher risk than adolescents without disabilities. *Child Abuse & Neglect: The International Journal*, 36, 4, 285–295.

Caldas, S. J. & Bensy, M. L. (2014). The sexual maltreatment of students with disabilities in American school settings. *Journal of Child Sexual Abuse*, 23, 4, 345–366.

Cashmore, J., Scott, D. & Calvert, G. (2008). Think child, think family, think community. From a child protection system to a system for protecting children. *Submission to the Special Commission of Inquiry into Child Protection Services in NSW (Vol. March).* Sydney: NSW Commission for Children and Young People, University of Sydney; Southern Cross University; University of South Australia.

Clapton, J. (2008). *A transformatory ethic of inclusion: Rupturing concepts of disability and inclusion.* Rotterdam: Sense Publishers.

Coulson Barr, L. (2012). Safeguarding people's right to be free from abuse: Key considerations for preventing and responding to alleged staff to client abuse in disability services. In D. S. C. Laurie Harkin (ed.), *Occasional paper No 1.* Melbourne: Office of the Disability Services Commissioner.

Dowse, L., Soldatic, K., Didi, A., Frohmader, C. & van Toorn, G. (2013). *Stop the Violence: Addressing Violence Against Women and Girls with Disabilities in Australia.* Background Paper. Hobart: Women with Disabilities Australia.

Dyer, K. & Teggart, T. (2007). Bullying experiences of child and adolescent mental health service users: a pilot survey. *Child Care in Practice,* 13, 4, 351–365.

Educational EdICTs. (2015). *SoSafe! Visual and conceptual tools for promoting social safety for people with intellectual disability, autism spectrum disorder, and for typically developing learners in early childhood.* Website viewed 27.6.15, http://sosafeprogram.com/index.html.

Fisher, K. & Robinson, S. (2010). Will policy makers hear my disability experience? How participatory research contributes to managing interest conflict in policy implementation. *Social Policy & Society*, 9, 2, 207–220.

Foley, K. R., Blackmore, A. M., Girdler, S., O'Donnell, M., Glauert, R., Llewellyn, G. & Leonard, H. (2012). To feel belonged: The voices of children and youth with disabilities on the meaning of wellbeing. *Child Indicators Research*, 5, 375–391.

French, P., Dardell, J. & Price-Kelly, S. (2009). Rights denied: Towards a national policy agenda about abuse, neglect and exploitation of persons with cognitive impairment. Sydney: People with Disability Australia.

Frohmader, C., Dowse, L. & Didi, A. (2015). *Preventing violence against women and girls with disabilities: a human rights perspective.* Hobart: Women with Disabilities Australia.

Goodley, D. & Runswick-Cole, K. (2011). Problematising policy: conceptions of 'child', 'disabled' and 'parents' in social policy in England. *International Journal of Inclusive Education,* 15, 1, 71–85.

Gore, M. T. & Janssen, K. G. (2007). What educators need to know about abused children with disabilities. *Preventing School Failure*, 52, 1, 49–55.

Graham, A., Powell, M., Taylor, N., Anderson, D. & Fitzgerald, R. (2013). *Ethical Research Involving Children.* Florence: UNICEF Office of Research – Innocenti.

Graham, A. & Fitzgerald, R. (2011). Supporting children's emotional and social well-being. Does having a say matter? *Children and Society*, 25, 447– 457.

Gray, A., Forell, S. & Clarke, S. (2009). Cognitive Impairment, Legal Need and Access to Justice*, Justice Issues*, Law and Justice Foundation, Paper No 10. Website viewed 29.8.13, xml.lawfoundation.net.au/ljf/site/.../JI10_Cognitive_impairment.pdf.

Griffiths, D. M., Watson, S. L., Lewis, T. & Stoner, K. (2004). Sexuality research and persons with intellectual disabilities. In E. Emerson, C. Hatton, T. Thompson & T. R. Parmenter (eds), *The International Handbook of Applied Research in Intellectual Disabilities* (pp. 310–334). West Sussex: John Wiley & Sons.

Grossman, S. F. & Lundy, M. (2008). Double jeopardy: a comparison of persons with and without disabilities who were victims of sexual abuse and/or sexual assault. *Journal of Social Work in Disability and Rehabilitation*, 7, 1, 19–46.

Hall, E. (2010). Spaces of social inclusion and belonging for people with intellectual disabilities*. Journal of Intellectual Disability Research*, 54, 48–57.

Hershkowitz, I., Lamb, M. E. & Horowitz, D. (2007). Victimization of children with disabilities. *American Journal of Orthopsychiatry*, 77, 4, 629–635.

Higgins, D. (2010). Sexuality, human rights and safety for people with disabilities: the challenge of intersecting identities. *Sexual & Relationship Therapy*, 25, 3, 245–257.

Higgins, J. R., Higgins, D. J., Bromfield, L. M. & Richardson, N. (2007). Voices of Aboriginal and Torres Strait Islander children and young people in care. *Promising practise in out-of-home care for Aboriginal and Torres Strait Islander Carers, Children and Young People: Strengths and Barriers (Paper 7)*. Melbourne, Australian Institute of Family Studies

Higgins, M. & Swain, J. (2010). *Disability and child sexual abuse: Lessons from survivor's narratives for effective protection, prevention and treatment*. London: Jessica Kingsley.

Hill, M. (2006) Children's voices on ways of having a voice: Children's and young people's perspectives on methods used in research and consultation. *Childhood*, 13, 69–89.

Hollomotz, A. (2011). *Learning Difficulties and Sexual Vulnerability*. London: Jessica Kingsley

Hopkins, P. E. (2010). *Young people, place and identity.* Abingdon, UK: Routledge.

Horner-Johnson, W. & Drum, C. E. (2006). Prevalence of maltreatment of people with intellectual disabilities: a review of recently published research. *Mental Retardation and Developmental Disabilities Research Reviews*, 12, 57–69.

Hunt, R. & Walsh, K. (2011). Parents' views about child sexual abuse prevention education: A systemic review. *Australasian Journal of Early Childhood*, 36, 2, 63–76.

Jemtå, L., Fugl-Meyer, K. S. & Öberg, K. (2008). On intimacy, sexual activities and exposure to sexual abuse among children and adolescents with mobility impairment. *Acta Paediatrica,* 97, 5, 641–646.

Jones, L., Bellis, M. A., Wood, S., Hughes, K., McCoy, E., Eckley, L., Bates, G., Mikton, C., Shakespeare, T. & Officer, A. (2012). Prevalence and risk of violence against children with disabilities: a systematic review and meta-analysis of observational studies. *The Lancet*, 12, 1–9.

Kellett, M. (2011). Engaging with children and young people. *Centre for Children and Young People: Background Briefing Series*, *No. 3*. Lismore, NSW: Centre for Children and Young People, Southern Cross University.

Khemka, I., Hickson, L., Casella, M., Accetturi, N. & Rooney, M. E. (2009). Impact of coercive tactics on the decision-making of adolescents with intellectual disabilities. *Journal of Intellectual Disability Research.* 53, 4, 353–362.

Kvam, M. H. (2000). Is sexual abuse of children with disabilities disclosed? A retrospective analysis of child disability and the likelihood of sexual abuse among those attending Norwegian hospitals. *Child Abuse & Neglect*, 24, 8, 1073–1084.

Kvam, M. H. (2003). *Sexual Abuse of children with disabilities: Summaries from four reports*. Oslo: Save the Children.

Lewis, A. & Porter, J. (2004). Interviewing children and young people with learning disabilities: guidelines for researchers and multi-professional practice. *British Journal of Learning Disabilities*, 32, 191–197.

Manders, J. E. & Stoneman, Z. (2009). Children with disabilities in the child protective services system: an analog study of investigation and case management. *Child Abuse and Neglect,* 33, 4, 229–237.

Marsland, D., Oakes, P. & White, C. (2007). Abuse in care? The identification of early indicators of the abuse of people with learning disabilities in residential settings. *Journal of Adult Protection,* 9, 4, 6–20.

Mepham, S. (2010). Disabled children: the right to feel safe. *Child Care in Practice*, 16, 1, 19–34.

Murphy, G. H., O'Callaghan, A. C. & Clare, I. C. H. (2007). The impact of alleged abuse on behaviour in adults with severe intellectual disabilities. *Journal of Intellectual Disability Research,* 51, 10, 741–749.

Murray, P. (2004). *Making connections: developing inclusive leisure in policy and practice*. York: Joseph Rowntree Foundation.

Notara, D. & Robinson, S. (2013). *The belonging project: report of outcomes*. Lismore, NSW: Northern Rivers Social Development Council.

Oosterhoorn, R. & Kendrick, A. (2001). No sign of harm: Issues for disabled children communicating about abuse. *Child Abuse Review*, 10, 4, 243–253.

Oulton, K. & Heyman, B. (2009). Devoted protection: How parents of children with severe learning disabilities manage risks. *Health, Risk & Society*, 11, 4, 303–319.

Robinson, S. (2012). *Enabling and protecting: proactive approaches to addressing the abuse and neglect of children with disability*. Melbourne: Children with Disability Australia.

Robinson, S. (2014). *In the picture: understanding belonging and connection for young people with cognitive disability in regional communities through photo-rich research.* Lismore, NSW: Centre for Children and Young People, Southern Cross University. Report for the National Disability Research and Data Working Group.

Robinson, S. & Chenoweth, L. (2011). Preventing abuse in accommodation services: from procedural response to protective cultures. *Journal of Intellectual Disability*, 15, 1, 63–74.

Safe4Kids (2015). *Safe4Kids Child Abuse Prevention Program*. Knowledge Practice Profile, Australian Institute of Family Studies. Website viewed 13.6.14 https://apps.aifs.gov.au/ipppregister/projects/safe4kids-child-abuse-prevention-program.

Sequeira, H. & Hollins, S. (2003). Clinical effects of sexual abuse on people with learning disability. *The British Journal of Psychiatry*, 182, 1, 13–19.

Shakespeare, T. (2014). *Disability rights and wrongs revisted.* Abingdon, UK: Routledge.

Shannon, P. & Tappan, C. (2011). A qualitative analysis of child protective services practice with children with developmental disabilities. *Children and Youth Services Review,* 33, 1469–1475.

Skattebol, J., Hamilton, M., Skrzypiec, G., Burnstock, T., Redmond, G., Jenkins, B. & Dodd, K. (2013). *Understanding children's perspectives on wellbeing: Phase One Report for the Australian Child Wellbeing Project.* Adelaide: Flinders University, The University of New South Wales and the Australian Council for Educational Research.

Sloper, P. & Beresford, B. (2014). Children who have disabilities. In G. B. Melton, A. Ben-Arieh, J. Cashmore, C. S. Goodman & N. K. Worley (eds.), *The SAGE Handbook of Child Research*. London: SAGE.

Sobsey, D. (1994). *Violence and abuse in the lives of people with disabilities: The end of silent acceptance?* Baltimore: Paul H Brookes.

Sobsey, D. & Mansell, S. (1994). Sexual abuse patterns of children with disabilities. *International Journal of Children's Rights*, 2, 1, 96–100.

Stalker, K. & Connors, C. (2005). Children with learning disabilities talking about their everyday lives. In G. Grant, P. Goward, M. Richardson & P. Ramcharan (eds.), *Learning disability: A life cycle approach to valuing people.* Berkshire, UK: Open University Press.

Stalker, K. & McArthur, K. (2012). Child abuse, child protection and disabled children: a review of recent research. *Child Abuse Review,* 21, 1, 24–40.

Stalker, K., Abbott, D., Beresford, B., Carpenter, J., McConkey, R. & Watson, N. (2012). Researching the lives of disabled children and young people. *Children & Society*, 26, 3, 173–180.

Sullivan, P. M. & Knutson, J. F. (2000). Maltreatment and disabilities: a population-based epidemiological study. *Child Abuse & Neglect*, 24, 10, 1257–1273.

Swain, J., Heyman, B. & Gillman, M. (1998). Public research, private concerns: ethical issues in the use of open-ended interviews with people who have learning difficulties. *Disability & Society,* 31, 1, 21–36.

Tisdall, E. K. M. (2012). The challenge and challenging of childhood studies? Learning from disability studies and research with disabled children. *Children and Society*, 26, 181–191.

UNICEF. (2005). *UN Secretary General's report on violence against children: Thematic Group on violence against disabled children*. New York: UNICEF.

UNICEF Innocenti Research Centre. (2007). *Promoting the rights of children with disabilities: Innocenti Digest No. 13*, Innocenti Digests. Florence: UNICEF Innocenti Research Centre.

United Nations. (1990). *United Nations Convention on the Rights of the Child*. Website viewed 13.6.14 http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx.

Watson, D., Abbott, D. & Townsley, R. (2007). Listen to me, too! Lessons from involving children with complex healthcare needs in research about multi-agency services. *Child: Care, Health & Development*, 33, 1, 90–95.