HARMS AND BENEFITS

Including children and young people with cognitive disability in research about personal safety and abuse preventions

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Background context:

Our work with children and young people with disability over the past several years has involved carefully building the conditions necessary for including a wide range of children and young people in research about personal safety and abuse prevention. While there is common agreement that children and young people have the right to be supported to give an informed view on matters about their own lives (Lundy & McEvoy, 2012), it is much less common that they are supported to do so on sensitive issues. This case study is about a project we did for the Australian Royal Commission on Institutional Responses to Child Sexual Abuse. The research was focused on what helps children and young people with disability and complex support needs to feel and be safe. You can find the project report in full here, and academic papers about it here and here.

Directly involving children and young people with disability in research concerning their lives is vital for ensuring that policies and programs are responsive to children's needs and lived experience (Briggs & Hawkins, 2005; Skattebol et al., 2013; Sloper & Beresford, 2014). Documenting the views and experience of children and young people with disability can also help to mitigate perceived silencing or minimisation of abuse and neglect. For example, their experience of abuse and neglect is sometimes downplayed or marginalised when other competing pressures either 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; Sloper & Beresford, 2014; Robinson & Graham, 2020; Sobsey & Mansell, 1994). The high rates of harm that children and young people with disability experience means that their participation is all the more important (Briggs & Hawkins, 2005; Mepham, 2010; Stalker & McArthur, 2012).

The ethical challenge:

Alongside the clear importance of including the perspectives of children and young people with cognitive disability and complex support needs in research of this nature sit several ethical and practical challenges. Not least among these: our focus was quite an abstract concept – explaining 'safety' to children and young people who experience the world in very concrete terms was challenging. To understand the experiences of children and young people who did not communicate (primarily) through speech required substantial adaptation to standard research methods. Service providers (and some family members) had low expectations of the capabilities of children and young people with disability to contribute to research about their lives, and recruitment was very difficult. We also knew that, given the high rates of harm experienced by children and young people with disability, a percentage of those involved in our study would be abuse-experienced and so considerable caution and sensitivity was needed.

In summary, the key ethical challenges for our team in this project in working with children and young people with cognitive disability and complex support needs were:

1. Explaining the concept of safety
2. Communication
3. Gate-keeping / expectations
4. Responding effectively to abuse-experienced participants

Choices made:

In order to respond to these challenges and understand the diverse perspectives of children and young people with complex support needs, we knew that we would need multiple methods. First, we were aware that children and young people with disability may be less likely to have experience of talking about personal safety than other children their age. We found little previous research and a lack of programs on personal safety education, protective behaviours training or safeguarding initiatives involving children and young people with significant disability. Therefore, we developed supporting resources and processes to explain the concept of personal safety to children with disability as part of the research process.

Second, to support communication and sharing of experiences, we developed a 'toolkit' of research methods for working with children and their families – a tailored compendium of research methods. Working with each child or young person and their supporter(s), we identified the methods most likely to resonate with them, and used these in combination to find out how they understood safety and the lack of it in their social worlds.

Interviews were conducted using a range of tools such as games and stimulus materials such as squishy balls, toys and drawing materials to minimise the formality of the experience and improve the comfort for children and young people. Alongside these more traditional approaches, we also used less direct approaches with some children, to learn from information gathered from and about their daily lives and time shared together with the researcher, supported by contextual information gathered from families/supporters. Therefore, individual and small group contributions were framed around the use of traditional and non-traditional interview approaches, using a combination over multiple meetings of:

- The information resource
- Game-based activities
- Pictorial mapping
- Photographic methods (photo elicitation and photo documentation)
- Guided collage (e.g. storyboards)
- Communication tools (e.g. Talking Mats)
- Walk-along interviews
- Participant observation
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(see Boxall & Ralph, 2009; Murray, 2004; Robinson & Notara, 2015; Robinson & Graham, 2020; Sloper & Beresford, 2014).

Finally, in both the research design and fieldwork processes, our team had a heightened level of awareness that children and young people may have experienced and/or witnessed abuse(s), potentially by a carer. We were conscious that the process of establishing rapport and a sense of trust between young people and researchers, which is important for the research process, may also lead to disclosures of abuse. We built the capacity of fieldworkers to be well prepared to take appropriate responsive action or to address concerns if young people do not recognise abuse in their lives. Family members were carefully prepared in the initial meeting that the researchers would take action on disclosures.

The research process also built in multiple options for engagement/disclosure, preferably with different support people present, to avoid any potential for perpetrators to influence children and young people in the study. For example, as part of the personal safety booklet we developed which included easy read resources about safety and abuse prevention, we included a final page which formed a personalised safety plan. This was completed as part of the interview suite, and left with children and young people as a resource.

Reflexive questions/considerations:

Principles of ethical research were very helpful in guiding our team in the choice and use of research methods for researching with children with higher support needs in this sensitive context. We found that:

- Having sufficient time to develop research relationships, through multiple visits with people with high support needs allowed information to emerge at a pace more comfortable for many children and young people.
- Methods such as pictorial mapping, photography and guided collage supported children and young people to see that even when they are talking about lack of safety, there are most often also safe people and places in their lives.
- An informal interview process, and game- and activity-based approach, supported children and young people to address issues and/or to avoid those which they found confronting.
- Developing and using tailored resources to help children and young people understand the concept under investigation (in this case, personal safety) helped to build knowledge and confidence, and left participants with useful information.
- Being alert to the importance of communication and reflection in addressing the complex ethical issues that may arise in research of this nature is critical.
- The role of supporters in interviews (families and other people close to children and young people) was of central importance for many participants with high support needs and, for some, was a window into their participation. This role, however, needed to be managed proactively by the researchers, with sensitivity and with respect for young people's autonomy and agency.

(Robinson & Graham, 2020; Robinson & Graham, 2019; Graham et al., 2013; Murray, 2004; Skattebol et al., 2013; Sloper & Beresford, 2014).

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