Research Insights

Safe at Home? Safety strategies used by people with intellectual disability

Summary

- This participatory research explored the ways in which people with intellectual disability keep themselves safe in the places where they live. People with an intellectual disability participated in the development of key aspects of the research, including the methodology, the easy-to-understand materials used in interviews and the analysis of information.
- The level of choice and control people felt they had over their living environment impacted on their feelings about personal safety. Those living in shared arrangements and those who required significant personal support had a lower sense of safety.
- It was the participant's surrounding circumstances, not their capacity, that had the most effect on putting their personal safety strategies in place. People's personal safety strategies appear to be more successfully implemented in more supportive environments.
- The lived experience of people with intellectual disability, and the challenges they face in keeping themselves safe, are important lessons in the context of the changes occurring in policy and practice in Australia, including the rapid move towards individualised funding and support.

Introduction

Feeling safe and strategies to keep yourself safe are important to us all. Where a person has a significant reliance on support staff and support services, or lives in a group home with other people, different strategies might be used and different challenges faced.

The Office of the Public Advocate partnered with Griffith University and the Office of the Adult Guardian to explore the ways in which people with intellectual disability keep themselves safe in the places where they live.

A small-scale participatory research project was undertaken that directly asked people with intellectual disability about their experiences.

The results of the study have been incorporated into an article in the *Scandinavian Journal of Disability Research*, written by Sally Robinson.[1]

Research design

The research employed an innovative and rights-respecting participatory methodology, which involved the participation of people with an intellectual disability in the design, data collection and analysis of information.

Group and individual interviews were conducted with 20 people with an intellectual disability who had varying support needs and life experiences. Nine practitioners and policy-makers responsible for accommodation and community living were also interviewed.

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[1] Sally Robinson,*'Safe at home? Factors influencing the safety strategies used by people with intellectual disability'*, Scandinavian Journal of Disability Research (2013) DOI:10.1080/15017419.2013.781958.

Research participants were accompanied by trusted support people at the group interviews, which were semi-structured and focussed on three core questions: What helps you feel safe at home? When don't you feel safe? What do you do when if you don't feel safe?

During the interviews, a safety booklet was distributed and perused. The booklet presented information about safety at varying levels: physical safety, safety in relationships, emotional abuse, and rules relating to services and to financial, medical and behaviour management. The booklet stimulated further discussion about safety issues and concerns and included a template for a short personalised safety plan, which research participants completed toward the end of the interview. The plan included contact details for people who could assist the research participants with any safety concerns.

With the assistance of people with intellectual disability, the following definition of personal safety was adopted and used in the safety booklet:

> "Feeling safe means different things for different people. Some people say that feeling safe feels like: no one is going to hurt you, people care about you, you know the rules, you have a say in the way things happen, people listen to you, people will help you if you have a problem."[2]

The research participants had varying demographic characteristics, backgrounds, living situations and support arrangements. The sample did not, however, include people with high support needs, communication impairments or people living in restrictive environments.

Literature review

There is a significant body of research focussing on the abuse and neglect of people with an intellectual disability. This research consistently highlights high rates of abuse and neglect of people with an intellectual disability and finds that there is often inadequate recognition and response by those who provide support services. Further to this, people with an intellectual disability frequently had little recourse to justice as victims.

Some features of living in supported accommodation have been shown to increase the risk of violence, abuse and neglect particularly where the accommodation is institutional in design, where there is a high reliance on others for intimate personal support and where there is a lack of choice and control.

Several studies identified that a lack of choice and control in key aspects of their home life was central to people's lived experience of harm. Exclusion of people with an intellectual disability from decisions relating to their home life is identified in the literature as a key risk factor for abuse and neglect.

Prior to the research conducted by Griffith University, there was limited research that engaged directly with people with intellectual disability. In particular there was a paucity of research that directly asked people with intellectual disability about how they recognise potential danger and their strategies for avoiding it.

Findings

Being safe at home

The research participants primarily associated locking doors and being safe from strangers with being safe at home. Locking doors was particularly important to female participants. Physical safety strategies including fire safety, fire alarms and evacuation procedures were also emphasised by participants.

As rapport was developed during the interviews, participants began commenting on safety in relationships as a significant issue in personal relationships and friendships, as well as with people with whom they shared housing. Eight of the twenty participants discussed their experiences of significant violence from people with whom they were familiar e.g. relative, friend, neighbour.

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[2] Ibid, p4.

Strategies to feel safe

Participants used *physical, relational and help-seeking strategies* to keep themselves safe at home. A large proportion of participants indicated that they used multiple strategies.

The most common *physical strategies* included locking doors (particularly when alone at home), fire safety plans and careful use of electronic appliances. Some men also talked about being prepared to take physical action, for example, keeping an item for self-defence by their bed at night. A number of participants spoke about avoiding potentially dangerous situations to avoid confrontation e.g. not leaving their house at night, locking their door if a neighbourhood argument started.

The *relational strategies* identified by participants included being with their family, having a say about who supports them, being able to rely on support workers and neighbours, having a positive relationship with people with whom they live, knowing who their friends are and only inviting trusted people into their room.

The *knowledge and help-seeking strategies* that were described by participants included understanding how to effectively make a complaint, knowing how to contact emergency services and being aware that they could contact a trusted person if something or someone makes them feel unsafe. While participants knew that they could make complaints, their experiences in doing so had left them with little faith that their complaints would result in any change.

Issues impacting the capacity to implement strategies

Choice and control

The amount of choice and control people felt that they had over their own living environment impacted on their feelings about personal safety at home. Being able to lock the door to keep unwanted people out of their home was important to the people who lived alone. People who lived in shared arrangements, particularly those who did not choose to live in shared accommodation, had a much lower sense of security. For example, one person structured their week around the roster of support staff and routines of co-tenants as they felt unsafe at home when no support staff were present.

The inability to negotiate a satisfactory solution to problems and make complaints that resulted in inaction undermined people’s sense of safety. The lack of power to negotiate care arrangements, make a complaint or make changes if they felt uncomfortable undermined the feeling of personal safety for several of the research participants.

Issues with support workers

Personal safety and the provision of personal care by support staff was a significant concern for some participants, especially those who required a significant level of assistance. Participants explained that they felt very uncomfortable when support staff did not provide them with thorough personal care and described how unsafe they felt when workers did not use manual handling equipment (e.g. hoists) properly. Some participants experienced abuse by support workers providing personal care.

Interrelationships problems

It was common for research participants to experience tensions in relationships, including intimidation, bullying and domestic violence. Sadly, several participants spoke about having their concerns about inter-relational problems downplayed.

Fear of harm

When discussing the issue of personal safety, many participants expressed their fear of the possibilities and realities of harm. Some participants, mainly women, were vigilant about the possibility of theft and felt the need to keep their doors locked at all times. Some people were afraid of prowlers and the possibility of someone entering their home at night, particularly those who relied on support staff to get out of bed.

While positive relationships with neighbours were a protective factor, relationships with neighbours were negatively influenced by government policy and administration. A large proportion of research participants lived in public housing and felt that they had little control over anti-social and threatening behaviour.

The perspectives of policy-makers and practitioners

Policy-makers and practitioners felt that the current approaches to supporting people with an intellectual disability in their home were limited. Approaches to harm were seen to be reactive, with a general focus on responding to instances of abuse or neglect. There were minimal policies that promoted personal safety or included proactive approaches to the protection of people with an intellectual disability from abuse, neglect and violence in their home.

Policy-makers explained that at a broader level, preventative health, community health and community service messages were not tailored or inclusive of the needs of people with an intellectual disability. This, along with a historical culture of dependency within disability services, had led to significant power differentials and a lack of information to enable people with an intellectual disability to use their own safety strategies.

Practitioners explained that people with significant levels of disability are not able to verbalise their feelings around a lack of personal safety. Instead, they may express themselves through self-harm, aggression or through being silent or compliant. Those who express their lack of personal safety through aggression may commonly become subject to restrictive practices in their own home, which increases their feelings of being unsafe.

Policy-makers raised the important issue of hearing the voice of people with an intellectual disability when measuring how successfully disability services are supporting people to be safe in their home. They identified the need to measure service quality for people with an intellectual disability using a human rights framework.

Insights for policy and practice

From listening to the participants of this study, researchers concluded that safety issues that related to problems in the general community were better resolved than those related to disability service provision. Participants felt they could draw on the same resources as the broader community – neighbours, the police, the Fire Brigade. More difficult however was negotiating care with disability support services. It was difficult for many participants with intellectual disability to put their safety strategies into action, not due to capacity, but to circumstance.

It was the participant’s surrounding circumstances, not their capacity, that had the most effect with respect to successfully putting their personal safety strategies in place. The environment in which people’s strategies are implemented can be a barrier to their success.

People’s personal safety strategies are likely to be more successfully implemented in more supportive environments. This requires the involvement of others to create safe cultures and environments that enable relationships and service structures that hear and respect the voice of people with intellectual disability.

The researchers highlighted the need for the lived experience of people with intellectual disability and the challenges they face in keeping themselves safe to be taken into account in the context of the changes occurring in policy and practice in Australia, including the rapid move towards individualised funding and support.

The researchers suggested the use of a human rights framework to better understand and measure the safety of people with an intellectual disability. Such a framework would view people as community members and not service users.

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