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### Safe at home? Factors influencing the safety strategies used by people with intellectual disability

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## Safe at home? Factors influencing the safety strategies used by people with intellectual disability

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Little is known about how people with intellectual disability understand personal safety, or what strategies they call upon when they do not feel safe in their homes. In this participatory research, 20 people with intellectual disability talked about the ways they keep themselves safe in the places where they live, and what helps them or makes it hard for them to stay safe. Interviews with nine disability policy-makers were also conducted to include a systemic perspective about how personal safety is addressed by funded disability support services. A series of factors either support people or make it difficult for them to put their strategies into action, influencing the degree to which they were able to draw upon their own strategies to protect themselves from potential harm.

**Keywords:** intellectual disability; personal safety; harm; abuse prevention; user views

### Introduction

While there is a limited body of research with people with intellectual disability about their experience of abuse and neglect, there is little research which asks people about how they take preventative action to avoid harm. Research with people with intellectual disability which works directly with them to look for the causes and consequences of abuse and harm has important implications for policy and practice in not only disability services, but more broadly for community safety strategies, public housing design and crime prevention.

In this participatory study, 20 people with intellectual disability were asked about how they understand personal safety, and about what they do when they do not feel safe at home. People who lived in a range of environments – in group homes, in boarding houses, in social [public] housing units and villas, with family, and in homes they own – shared their experiences and perspectives about how they keep safe, and what works and does not work well for them. Policy-makers and practitioners also contributed a systemic perspective to the study about how the disability support system promotes the personal safety of people with intellectual disability in the Australian state in which the research took place.

This paper discusses the results of the study. The background to the study is briefly described, followed by a literature review which situates personal safety and self-protection strategies within the abuse and neglect research literature. The results

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of the study are presented, with priority given to the experiences and perspectives of people with intellectual disability. A series of implications arising from the results are discussed which have relevance for theory, policy and practice.

### **Background**

In previous research completed with people with intellectual disability about emotional and psychological abuse and neglect (Robinson 2010), some participants raised strategies they draw upon to keep themselves safe when they feel under threat of violence or abuse in their homes. The study which is the subject of this paper was conducted because it was important to the people who participated in the abuse research that more work was done about how they use their own strategies to keep themselves safe – they did not feel that services took account of their capacities or built from their experiences.

Consequently, this study aimed to explore with people with intellectual disability how they understand safety in their homes, and the strategies they use to keep themselves safe when they feel under threat at home. How well do these strategies work for them? What helped and hindered people in using the strategies they have developed? The study focused on people with intellectual disability who received some support from funded services to live at home. We also spoke with policy-makers about their perspectives on personal safety for people with intellectual disability. The methodology section provides more detail about the approach of the study.

### **Literature review**

There is a significant body of research about the abuse and neglect of people with intellectual disability. While prevalence estimates vary widely, this literature consistently shows that people with intellectual disability experience abuse and neglect at high rates, that the recognition and response to abuse and neglect by those who support people with intellectual disability is often poor, and that they have little recourse to justice as victims (Brown 1999, 2004; Conway, Bergin, and Thornton 1996; Coulson Barr 2012; McCarthy and Thompson 1996; Sobsey 1994, 2000).

The terms violence, abuse and neglect are at times used interchangeably in the literature, and it may be useful to distinguish between them for the purposes of this paper. Violence is used here to refer to harms of an extreme nature (such as physical and sexual assaults), abuse to refer to acts of *commission* (theft, emotional and verbal ill treatment, restrictive practices, financial mismanagement, etc.), and neglect to refer to acts of *omission* (physical or wilful neglect or the failure to provide for personal growth) (Chenoweth 1995; Fawcett 2008; Jenkins and Davies 2006).

Theoretical understandings of the social, cultural and structural roles and places of people with intellectual disability underpin the experience of harm. Social constructionists argue that the abuse of people with intellectual disability continues due to their extreme marginalization and their positioning as ‘other’ or less human – that they have been categorized through cultural practices as being somehow fit for treatment which would be deemed inappropriate for someone without an intellectual disability (Clapton 2008; Clegg 1993; Goodley 2011).

At worst, these constructions result in the oppression, isolation and dehumanizing of people with intellectual disability, substantially increasing the conditions under which abuse is likely to occur and recur (White et al. 2003).

Some features of living in supported accommodation have been shown to increase the risk of violence, abuse and neglect, including institutional or isolating service design, having a large number of staff provide support to you, relying on others for intimate personal support, and receiving intensive support for challenging behaviour (Beadle-Brown et al. 2010; White et al. 2003). Added to these are broader social drivers of harm, such as poverty, inadequate social housing and social stereotypes of vulnerability (Fawcett 2008; Women with Disabilities Australia 2007).

Central to people's lived experience of harm in several studies is a lack of choice and control in key aspects of their home life – the staff who are employed to work with them, the people with whom they share their home, or the places in which they live (Coulson Barr 2012; Malacrida 2005; McCarthy and Thompson 1996). This is not to suggest that all people with intellectual disability can easily make these large scale decisions, but exclusion of them (and/or their families and other supporters for people with high support needs) from decisions about these key safety features is clearly shown in existing research as a risk factor for abuse and neglect (Conway et al. 1996; Sin et al. 2009; White et al. 2003).

A pressing need has been identified in existing research for a stronger focus on prevention and the protection of people with intellectual disability from abuse and neglect (Bruder, Stenfert Kroese, and Bland 2005; Powers and Oswald 2004; Sobsey 1994). In the context of abuse prevention, it appears there is little research which asks people with intellectual disability about how they recognize potential danger and their strategies for avoiding it.

A limited amount of research engages directly with people with intellectual disability and reports on their lived experience of harm. This work, while very valuable, most often focuses on their experiences of violence, abuse and neglect, drawing lessons for policy and practice from the experiences of victims (Malacrida 2005; Mitchell, Clegg, and Furniss 2006; O'Callaghan, Murphy, and Clare 2003; Sin et al. 2009).

Much of the literature around self-protection and people with intellectual disability relates to the teaching of protective behaviours programmes in order to protect people against sexual assault or other forms of harm. For example, there are a significant number of training packages and programmes on self-protective behaviours for children and adults with intellectual disability which build on principles of abuse prevention (Collins and Walford 2008; Dixon et al. 2010).

Research on the experience of harm also connects to a literature on protective and preventative action against abuse, neglect and violence against people with intellectual disability. Models of abuse prevention arising from public health which focus at primary, secondary and tertiary levels recognize the need for a multi-layered, multi-strategy approach to a complex problem, advocating community level responses, responses geared to specific groups at higher risk of harm, and resources and attention to assistance for people who have experienced harm for their support and recovery (see for example, Fitzsimons 2009). Other approaches emphasize the relational nature of protection – the importance of having engaged, supportive people in your life and the value of unpaid relationships and meaningful community engagement (Coulson Barr 2012; MacArthur 2003; Mansell 2006; Robinson and Chenoweth 2011).

### **Methodology**

The study used a participatory approach, relying on qualitative group and individual interviews with people with intellectual disability who had a range of life experiences and support needs, and also with policy-makers and practitioners.

Key aspects of the study were developed with the support of people with intellectual disability and policy-makers, including easy English materials, interview schedules and sampling design. Specialist advice was sought from researchers with intellectual disability on the proposed research design, interview guide and easy read booklet, to ensure it would be accessible to participants. A small reference group of systemic advocacy representatives advised on the project development.

A key element of the research design was defining personal safety. With the assistance of people with intellectual disability, for this project a definition of personal safety was developed and used in the safety book as follows:

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.

A range of ethical implications was considered in the design phase of the study, including obtaining informed consent, confidentiality, balancing harm and benefits, and ensuring people were offered support to counter harms in their lives which they raised in the interviews (if this was not already in place). These were addressed through both the university ethics committee framework, and through taking a heuristic approach to ethics in the study, and paying particular attention to the creation of an ethical research environment (Clegg 2004).

In order to capture a range of perspectives, the original aim was to recruit 30 people to the study, with an even mixture of people who use low levels of funded support to assist them in community living ('drop in' support), people who used higher levels of funded support for daily living in community housing environments (group homes, shared tenancy and individual funding arrangements), and people who spent significant periods of their childhoods in formal 'care' environments. It was also hoped that family members and advocates of some of these people would be included in interviews, with the agreement of the 'core' participants.

The study was promoted through a range of service, advocacy and information organizations, through direct contact with key stakeholders, and by direct invitation to self-advocacy groups. Due to a concern about not wanting to refuse participation to anyone due to over or inaccurate recruitment, the research was not 'broadcast' promoted, but sent through targeted channels.

Recruitment of people with intellectual disability who were willing to talk about personal safety proved more complex and difficult than anticipated, despite previous experience in several other research projects with similar groups. Twenty people with intellectual disability participated in the study, through group and individual interviews. Trusted support people were present in the group interviews, at the wish of participants.

This was very valuable in helping people to feel comfortable, and in drawing out shared histories. Only one person offered to provide contact details for follow up with a family interview – due to this low response, family interviews were not pursued.

Table 1 shows the backgrounds and characteristics of participants.

Interviews with people with intellectual disability were semi structured, built around three key questions: what helps you to feel safe at home? When don't you feel safe? If you don't feel safe, what do you do? The easy-read and pictorial resource about personal safety was used to support the interview process, and left with participants as a resource.

Little prompting was required in the group interviews. People were both interested in the topic and keen to share their experiences. More confident group

Table 1. Background and characteristics of people participating in the study.

Gender	Male	12
	Female	8
Culture	Aboriginal and Torres Strait Islander	None known
	Cultural and Linguistically Diverse Background	None known
Age	26–35	5
	36–45	7
	46–60	8
Additional disability (all had intellectual disability)	Physical	5
	Sensory	1
	Communication	3
	Psychosocial	3
Background	Grew up with family	16 <sup>a</sup>
	Grew up with significant period in care environment	4
Current support	No paid support	6
	Receiving small amounts of paid support (weekly or twice weekly)	9
	Living in a group home or similar with >12 hrs paid support/day	5
Current housing	Social housing	9
	Community housing	1
	Boarding house/hostel	2
	Group home	3
	Private own/rental	3
Housemates	Family home	2
	Live alone	12
	Sharing with someone not of your choice	5
	Sharing with someone of your choice	1
	Living with family	2

<sup>a</sup>Several people did not discuss their background in detail, and we did not press them. We have assumed, based on conversation, that they did not grow up in care environments.

members spoke quickly about their experiences, and had established processes in their group for hearing the voices of quieter members (asking for further ideas; passing a ‘talking stick’) which encouraged further contributions at key points. The interviews each started with the three broad questions detailed above, and sub-questions relevant to the responses provided by participants were asked to tease out how effectively people felt their strategies had worked. Once these questions were exhausted, the safety book was distributed and leafed through together for further inspiration.

The booklet addresses safety at a range of levels – physical safety, safety in relationships, emotional abuse, rules in services, with medical management, with behaviour management and with financial management. This gave rise to further examples of safety concerns in specific areas. The final page of the book is a short personalized safety plan which each person completed as a closing activity of the interview, which included people they could call on in case of safety concerns.

A similar process was followed for individual interviews, although clearly without the need to consider group dynamics or hear multiple voices. It is noteworthy that on this sensitive topic, the group interviews seemed a more positive experience for participants – while it did not appear that the research caused distress to any participants, the support provided by members of the group to each other was evident during the interview process through their comments and interaction. Social engagement before and after the interview with the group also helped assess people’s level of comfort with the material we discussed. This is similar to the experience described by Hall (2005) in his group research with people with intellectual disability. This view can only be generalized from this study with considerable caution, due to the small number of individual interviews conducted (four), although it is consistent with previous research (Robinson 2010).

Furthermore, nine policy-makers and practitioners responsible for accommodation and community living participated in group and individual interviews, offering a systemic perspective on how funding and support was structured in the state that the research took place. Policy-makers and practitioners were asked about how well they felt people with intellectual disability understood personal safety, how well developed their personal safety strategies were, facilitators and barriers to implementing those strategies, and about the existence of policy addressing these topics.

### ***Limitations***

This study does not canvass the perspectives of people with high support needs, people with communication impairments or people living in restrictive environments. Existing research highlights the risks that these groups are living with, in terms of both a lack of personal safety and of ways to make their voices heard about abuses of their rights to safety (Coulson Barr 2012; Mitchell, Clegg, and Furniss 2006; O’Callaghan, Murphy, and Clare 2003). There is a clear need for further research which explores the perspectives of people in these groups.

### **Results**

All participants in this study felt that they knew a number of ways to keep themselves safe, although many identified areas where they had concerns about how well their strategies were able to be put into place.

Clear themes emerged from the interviews with people about how they understood personal safety and acted to keep safe at home; the strategies they have used to keep safe; how well they felt their strategies worked for them; and key issues affecting their capacity to act on feelings of risk and lack of safety at home. These are discussed below in turn.

All names attributed to participants in the study used in this paper are pseudonyms in order to maintain their privacy. Quotations are direct statements as made by participants without alteration.

### *What is being safe at home?*

In response to this question, people primarily thought in terms of locking doors and being safe from strangers. After reflective discussion, safety in relationships emerged as a significant area of concern.

#### *Physical safety*

The first and strongest emphasis by participants with intellectual disability was on physical safety strategies (fire safety, alarms, emergency evacuation plans and so on) – practical, physical things you do to keep safe. When asked whether these were implemented, some people knew where their fire safety plan was, one person had his own fire safety plan developed for his own home, and several people talked about the importance of keeping doors locked, especially at night. This was particularly important to women:

At night time, make sure everything's locked up, you have to make sure of that. These days, if you have something unlocked, anyone could come in, you know? (Brenda)

Other people were less sure that physical safety strategies were in place – two people who shared a group home with two other residents, and who all used wheelchairs, did not know of a fire safety plan for their home. They questioned whether they would all be safe in the event of a fire, and did not know how they would get out.

#### *Safety in relationships*

While participants talked frequently about 'stranger danger', there was little discussion about domestic violence, abuse and neglect, even though 40% of participants related direct experience of these forms of violence.

With the development of some rapport in the interview process, safety in relationships emerged as a significant issue in people's lives, both within personal intimate relationships and friendships, and more widely with co-residents in shared housing. Safety in relationships is addressed in the easy English resource used in the interview process, prompting discussion with participants. This was not otherwise independently identified by many participants, perhaps because it is very personal and people were embarrassed by the failure of relationships to conform to community standards, rather than because people do not recognize it as an issue. Eight people talked about significant violence in their lives from people they knew well. For example, Kelly was supported to take out an apprehended violence order against a previously close friend after several assaults, Theresa relied on a relative to

protect her from another abusive relative who has previously assaulted and robbed her, and two people talked about direct experiences of being physically assaulted by neighbours. Frank's comment was indicative of the feeling of several people about needing to be 'on guard':

You have to know who your friends are. Cause where we are [boarding house/hostel], not everyone's a friend. Some people are very nice, but some are not. Some are bullies... (Frank)

### ***What helps you feel safe?***

When asked what helps them to keep safe, there were three kinds of strategies people described using – physical, relational and help-seeking. There are a range of strategies identified here, and a significant proportion of participants identified multiple strategies – that is, people drew from a suite of strategies in identifying how they would keep themselves safe at home.

#### *Physical strategies*

People were quick to identify physical safety strategies such as locking doors, especially when no one else is home; having a fire safety plan; and, being a careful user of electrical appliances. Less commonly, men also talked about taking physical action, such as keeping something besides your bed to hit someone with if they come into your room at night. People also talked about physically removing themselves from potentially dangerous situations and as a way to avoid confrontation – for example, not going out at night, or going inside and locking the door if a neighbourhood argument started.

#### *Relational strategies*

Participants also identified relational safety strategies. These included being with your family; being able to employ the workers and have a say in who works with you; being able to rely on staff; having a good relationship with the people you share your home with; only having people in your room that you can trust; knowing who your friends are; and being able to rely on your neighbours.

#### *Help-seeking strategies*

The third type of strategy people identified were knowledge and help seeking strategies. These included being able to complain effectively; knowing how to contact emergency services on your phone; and telling someone – like your mum – if something happens that makes you feel unsafe. The experience of several participants of making complaints, however, was not encouraging, and they had little faith about complaints resulting in change.

#### ***Putting plans into action***

There was a diverse range of perspectives among participants about putting strategies into action. While a small number of people felt confident, and practiced,

in using personal safety strategies (particularly avoiding confrontation and removing themselves from potentially difficult situations), more commonly people were not confident about putting their strategies into action. Two examples highlight this:

Sometimes neighbours make me feel safe, but when they're not there, you get a little bit scared. When you get scared, you don't know what to do. (Brenda)

Rhonda talked about a sleepover staff arrangement, and how she feels isolated at night. She saw someone at her bedroom window, twice, and was terrified, but still unwilling to disturb staff who were on-call to support her, but asleep.

### ***Key issues affecting people's capacity to act when they do not feel safe***

People's responses to questions about what happens when they do not feel safe fell into a number of clear themed areas: lack of choice and control; problems with paid staff; inter-relational problems (such as bullying and victimization); and fear.

#### ***Lack of choice and control***

People's feelings about personal safety at home were impacted by the amount of choice and control they felt they had over their own living environments. For those who lived alone, being able to lock the door and keep out anyone they did not want in their home was very important. For those who shared, particularly those who did not choose who they shared with, a sense of personal safety was much less securely felt. For example, Mark structured his week according to staff rosters and the routines of his co-tenants, going out when there would be no staff at home as he felt unsafe at home without staff present.

The lack of ability to negotiate a resolution to problems which was satisfactory in the eyes of participants was not only frustrating, but also undermining of their sense of safety. Angus had complained to both his service and to police about a night-time neighbourhood prowler on several occasions, but apart from being placed on a list at the office of 'clients in danger', said he had received no practical assistance to deal with his fear.

Similarly, the lack of personal power to negotiate care, to make changes if feeling uncomfortable, to complain, or to move house was undermining of personal safety for several people. This is eloquently illustrated by the following exchange:

Sally: Do you get a lot of people coming to the door that you don't know?

James: Only the carers.

Frank was injured on the morning of our interview when he fell on slippery stairs at his home, which were not properly maintained by the owner of the facility in which he lives. Both Frank and the staff who work there were angry, as they have asked for the owner to fix the problem before now, as Frank is not the first person to fall and be hurt on the stairs.

#### ***Problems with paid staff***

Personal safety and the provision of personal care by paid staff were a pressing concern for some participants, particularly people who required hoisting or

significant levels of assistance. They talked about how uncomfortable it made them feel to have workers fail to help them thoroughly with personal care, and how physically unsafe they felt if workers did not take the time or trouble to use manual handling equipment properly.

For some, this escalated to abuse:

Rhonda: I'm sorry about this, but a staff member abused me, and I didn't like it. And I said,

'look, this is inappropriate, for me to be abused'. And at the moment, I am still being verbally abused by the staff member, and I don't even know what to do, I don't know how to handle it, what to say, or whether to just walk away... I've just about had enough of it. I just feel like saying 'look, if you don't feel like doing anything for me, just say so.

Sally: That's a terrible situation, Rhonda.

Rhonda: You know, it's, how can I put it? It gets a little bit tiring, and a little bit boring and a little bit – and I think something, for me, it should be stopped. And I don't like being abused, I don't like being talked to like that. It's very horrible. And I mean, what am I supposed to do?

Several people talked about the difficulty of negotiating poor professional practice of staff. Four people had experience of workers bringing their friends into their homes uninvited while they were working, which they felt both uncomfortable about and unable to take action on. Underlying this discussion was the feeling that these practices created a climate of disrespect.

When asked about what they would do if a worker stole money, people said they would talk to the coordinator of the service. Several people had, however, been in the position of making a complaint about a staff member, with poor outcomes. Comments on the complaint process included 'they all back up each other', 'it's your word against theirs' and 'they go and work in another service straight away'.

### *Inter-relational problems*

Tensions in relationships were commonly related by people, including being bullied and intimidated by co-residents and for one person, family domestic violence. In seeking help from services and families several people talking about having concerns minimized or downplayed:

It's hard to get our point across when we are in trouble. Because we have a disability and we can't present ourselves as a normal, we get mixed up. We get fobbed off. (Steven)

### *Fear*

In talking with people about personal safety, most people also talked about their feelings, predominantly being fearful of both the possibilities and the realities of harm.

Some people, especially women, were very highly vigilant about the possibility of theft, and saw the need to keep doors locked at all times to prevent petty theft from wallets and the like. Several people were very afraid of prowlers and the possibility of people coming into their home at night, particularly people who also had physical

impairments which meant they relied on support staff to get out of bed. Sadly, one person related that the service he received support from told him that his mother had made him unduly frightened, and that he needed to see a psychologist to address this fear. He did not agree with this view.

Relationships with neighbours were an area frequently raised in interviews. While also a protective factor when relations are positive, at times relations with neighbours were negatively mediated by government policy. A significant proportion of participants lived in social [or public] housing units or villas, overseen by the Department of Housing. This meant in practice that 'bad' neighbours moved in and out, there was little control over anti-social and threatening behaviour, and sometimes high movement in the neighbourhood.

In the social housing complex Stuart lives in, another unit is used as short-term housing by mental health services. Five or six people at a time stay there without support, and at times cause a lot of turmoil. Although complaints to authorities result in people being taken away to hospital, more people come to replace them, and Stuart says:

They go off their rocker 24/7 . . . Then you've got to ring up the police, the fire brigade, the ambulance, to get them out. It's very frightening. They're very dangerous too.

These emerging themes highlight some critical issues for the prevention of violence, abuse and neglect in the lives of people with intellectual disability, including the importance of choice and control; critical tensions in negotiating relationships with key people in order for people with intellectual disability to feel, and be, safe; and barriers and facilitators to putting strategies into action.

### *Perspectives from policy-makers and practitioners*

The shared view of policy-makers and practitioners interviewed in this study is that current approaches to supporting people with intellectual disability in their homes take severely limited account of concepts of personal safety.

A reactive approach was taken to the experience of harm, with policy and procedures in place to cover how services and staff respond to individual instances of abuse and neglect of people using disability services in the Australian state in which the research took place. No policy was in place to promote personal safety or proactive approaches to the protection of people from violence, abuse and neglect in their homes.

At a broader level, policy-makers pointed out that population strategies which promote personal safety at home did not include people with intellectual disability, and preventative health, sexual health and large-scale community service messages (such as domestic violence campaigns) are not tailored with this audience in mind. Partnered with the historical legacy of the dependency culture of disability services, the shared view of policy-makers was that lack of information and significant power differentials work against people with intellectual disability using their own strategies to keep safe.

Two participants who have previous expertise in working with people with intellectual disability with high support needs pointed out that feelings of a lack of personal safety are unlikely to be verbalized by people with significant levels of disability. The consequent self-protection strategies used by people in this group can

be expressed through self-harm, aggression or acquiescence. For those who express their lack of personal safety through aggression, a common consequence is to become subject to restrictive practices in their homes – to be restrained either physically or with medication – increasing their feeling of unsafety.

The most successful examples of the promotion of personal safety at home that policy-makers provided were connected to broader philosophical drivers around community connectedness and inclusion. Personal safety at home was a collateral benefit of a broader inclusion agenda. In speaking of a highly successful community housing project, a policy-maker said:

A whole series of interconnected things were happening there – one of the biggest safeguards was lots of people were involved. Neighbours were involved, engaged. That's what you're aiming for – to grow, support, nourish something. And what I saw come out of that was people actually speaking up, rather than going in to their room and shutting their door.

Policy-makers independently raised the importance of hearing the voice of people with intellectual disability in human and policy terms in measuring how well disability services are supporting people to be safe at home. They talked about the limitations of current compliance frameworks for service quality, and saw the need to measure quality for people with intellectual disability through a human rights lens to counter the 'weird service language and culture' that the disability service sector has developed which sits separate to the broader community, and which creates a different set of expectations for people with intellectual disability than for other community members.

### **Discussion**

When asked about safety, people with intellectual disability most readily identified physical safety and 'stranger danger' strategies to keep safe. However, when talking about their experiences of harm, or when they felt uncomfortable or under threat, commonly they spoke about people they knew as the source of the problem. There may be a disconnect between the safety information people receive, their understanding of personal safety strategies, and their lived experience of dangerous, or potentially dangerous situations.

Safety problems that people with intellectual disability in this study described which related to problems in the general community were better resolved than those within disability services. People were able to draw on the same resources as do other people in the broader community – neighbours, the police, the Department of Housing, the Fire Brigade – to get action to resolve difficult situations. The more intractable problems in their lives revolved around difficulties in negotiating care relationships within disability services that spanned a continuum from tense to abusive. Many participants gave examples of abuse in their lives which they had attempted to resolve through either negotiation with workers or complaining to managers, without success (see Results section).

At a policy level, disability support services prioritized responding to instances of abuse and neglect, rather than promoting personal safety. This is to an extent reflective of the research landscape, where a strong focus (by virtue of urgency) has been on responding to violence and abuse already experienced, rather than focusing

on prevention. While it is of course essential that people who experience violence, abuse or neglect receive prompt, effective and compassionate support, strong prevention work is an important missing component.

While people have developed strategies to help them to stay safe within their sphere of influence, there are many elements of their lives which remain outside of their control. Relations with paid workers are largely controlled by either bureaucracy or by the dominant power relations between workers or managers and people who use services. Even where relations are positive and supportive between the two parties, the unequal nature of the relationship means that it is difficult for people with intellectual disability to put their personal safety strategies into place unless they are well received by the staff, manager or service.

Policy and practice in disability services need to be geared to the development of supports which engage people in their communities as citizens, in a range of roles and relationships. However, the control which is vested by others in the lives of people with intellectual disability (often expressed through support) needs to be acknowledged, and safeguards put in place to maximize protective features while protecting against the reality that a certain level of vulnerability to abuse will always be present in the lives of some people with intellectual disability.

Of course, feeling safe is about more than being free from violence, abuse and neglect. The importance of social connectedness was a feature which emerged from the research which was not identified by participants with intellectual disability, but which was a strong feature of interviews with policy-makers and practitioners. The social capital described by participants with intellectual disability in talking about their voluntary work, social groups and connection to advocacy groups all shared common elements of recognition and valuing – important in helping people to feel socially included and confident, and connected to personal safety in several ways. In not being alone, having someone to ask where you are if you are late or do not turn up when expected, neighbours who watch out for you and so on, people are less isolated, better protected and more engaged as community members.

This resonates directly with an established literature on protective and preventative action against abuse and neglect in the lives of people with intellectual disability. This centres on the importance of having active, engaged supporters in your life, and the value of community and unpaid relationships. There are clear implications for policy and practice here – supportive relationships outside of disability systems are protective (Coulson Barr 2012; MacArthur 2003; Mansell 2006; Robinson and Chenoweth 2011).

## **Conclusion**

There are key insights for theory, policy and practice which can be drawn from the lived experience of people who have navigated the service system as residents. It is important, however, to acknowledge that the climate or environment in which people's strategies are implemented is a key facilitator or barrier to their success. With the changing policy and practice environment in Australia and a now rapidly increasing move towards individualized funding and support, we should expect to see people with intellectual disability living lives in the community which more closely mirror those of other community members, and which are less segregated. New responses to promoting personal safety and to preventing harm are needed which reflect these changes.

It is difficult for people with intellectual disability to put some of their personal safety strategies into operation, not due to capacity, but to circumstance. The relational dynamics involved in keeping safe – the social, structural, political, interpersonal issues and barriers which interact with strategies – can militate against the successful use of tools which might, in more supportive environments, work effectively. People with intellectual disability cannot do it on their own. Other people need to be involved in creating safe spaces, cultures, environments, enabling relationships and service structures in which people's voice is heard and respected. What is clear from this study is that such a task needs to build from their lived experience and perspectives.

Measuring progress in promoting personal safety and preventing harm is also of great importance. Using a broad human rights paradigm to both understand and to measure safety and harm will help in conceptualizing people with intellectual disability as citizens rather than service users, with all the rights and entitlements this includes.

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