Feeling safe, acting safe

Strategies used by people with intellectual disability to keep safe at home

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Framework for today’s paper

• The project
• Background to the research
• The research results – What helped? What made it hard?
• What did we learn? How might this help make life safer for people with intellectual disability?
Background to the research

• Arose from an earlier study on emotional abuse and neglect
• Some research with people about their experience of abuse
• A gap in the research – a clear need for more work about prevention.

• We don’t know what people with intellectual disability do to avoid harm. How do people stay safe?

• Funding: The Forde Foundation; The Queensland Public Advocate; The Queensland Adult Guardian
This study is part of a bigger picture

- We do know:
  - Many people experience violence in their homes
  - This is not well recognised or responded to
  - People often don’t get good results with the police or the law

  **Wider causes**

- Othering
- Some features of supported accommodation
- Broad social drivers of harm – poverty, social housing, social stereotypes
- Lack of choice and control
The project

• 20 people with intellectual disability talked to us in focus groups and interviews about:
  – What helps you to feel safe at home?
  – When don’t you feel safe?
  – If you don’t feel safe, what do you do?

• 9 policy makers and senior service providers also talked to us about how well disability service systems help people to stay safe.
Getting advice

• People with intellectual disability advised us on:
  – What questions to ask
  – What to include in the safety book, and what words to use
  – Whether to have interviews or focus groups

• Systems advocates and service providers advised us on:
  • Who to ask to be in the study
  • What questions to ask
  • How the project was working
Thinking about feeling safe at home

Feeling safe at home: think about what feelings you may have if you are not safe.

What is feeling safe at home? Feeling safe means different things for different people. Some people might feel safe if they have a happy family. Other people might feel safe if they have a secure home environment. Still others might feel safe if they have a good support system of friends and neighbors.

Feeling safe in your body: think about what feelings you may have if someone is going to hurt you.

Feeling safe in your heart: think about what feelings you may have if someone is going to get angry with you.

Feeling safe in your head: think about what feelings you may have if someone is going to say that feeling safe feels like.

People will help you if you have a problem. People listen to you. You have the right to say that you want to stay safe. You can be safe. You are never alone. You can ask for help. You do not have to stay in a situation that makes you feel unsafe.
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<tr>
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<tr>
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<td></td>
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<tr>
<td></td>
<td>Living in a group home or similar with &gt;12hrs paid support/day</td>
<td>5</td>
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<tr>
<td>Current housing</td>
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<tr>
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<td>Group home</td>
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<tr>
<td></td>
<td>Private own/rental</td>
<td>3</td>
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<td></td>
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<td></td>
<td>Sharing with someone not of your choice</td>
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<td></td>
<td>Living with family</td>
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* 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.
Results of the research

• Everyone felt they knew a number of ways to keep themselves safe.

But...

• There were several areas where they had concerns about how well they could put their strategies into place.
What is being safe at home?

• Being physically safe – fire safety, alarms, locking doors at night.
• ‘Stranger danger’
• Having safe relationships – hard to talk about, but violence here a common experience (8 people).

‘You have to know who your friends are. Cause where we are, not everyone’s a friend. Some people are very nice, but some are not. Some are bullies.’

Frank
What helps you keep safe?

• **Physical strategies** – locking doors; having a fire safety plan; being careful with electricity; avoiding confrontation; self-defence

• **Relational strategies** – being with your family; choosing your own workers; getting on with your fellow housemates; being able to rely on your neighbours

• **Help-seeking strategies** – complain; call 000; tell someone who can help
Putting plans into action

• A few people had success and felt confident using their strategies
• More people weren’t confident to take action:

_Sometimes neighbours make me feel safe, but when they’re not there, you get a little bit scared. When you’re scared, you don’t know what to do._

Brenda
What made it hard?

- Lack of choice and control
  - Being able to lock your own door was very important
  - If you can’t choose who comes in and out of your house, it’s very hard to feel safe
  - Lack of personal power to negotiate care, to make changes if feeling uncomfortable, or to move house

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

James: *Only the carers*
What made it hard? (2)

• Problems with paid staff
  – Personal care done either incompletely or dangerously
  – Negotiating poor professional practice of staff
  – Not having complaints about staff listened to

 they all back up each other

Peter
What made it hard? (3)

• Inter-relational problems
  – being bullied by people you live with
  – domestic violence
  – having your concerns 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
What made it hard? (4)

• Fear
  – What might happen
  – Prowlers
  – Fear of neighbours, especially in social housing

_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._

Stuart
What did policy makers & practitioners say?

• Current approaches to supporting people in their homes
  – Take severely limited account of personal safety
  – Are reactive, not preventative

• Lack of information and power differentials work against people using their own strategies successfully

• A lack of personal safety in people with high and/or complex support needs may be expressed as aggression or frustration, and responded to with restrictive practices
What would help?

• Community connectedness and inclusion
• Personal safety at home is a collateral benefit of a broader inclusion agenda
• Measuring service quality through a human rights lens, and listening to the voice and experiences of people with disability
What did we learn?

For people with intellectual disability

• There seems to be a disconnect between the safety information people receive, their understanding of safety strategies, and their lived experience of safety and harm
• It was harder for people to get safety problems sorted out in disability services than in the wider community
• Importance of choice and control in this context
What did we learn?

For policy and practice

• Disability services respond more to instances of abuse and neglect, rather than promoting personal safety
• There are critical tensions in negotiating relationships with key people in order to people to feel, and be, safe
• People with intellectual disability do not feel listened to or responded to when these relationships are not working
Concluding thoughts

• Most people in this study had strategies to stay safe within their sphere of influence
• However, many areas of their lives remain outside of their control
• The climate in which people’s strategies are implemented is a key facilitator of their success
• As individualised approaches roll out, the promotion of personal safety is a critical concern, but one which is so far largely absent from policy debate
• People with intellectual disability have an important voice in this agenda
To read the journal article: Scandinavian Journal of Disability Research - new articles or http://works.bepress.com/sally_robinson/63/

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