

Insult and injury:

emotional and psychological abuse and neglect of people with intellectual disability living in disability accommodation services

Sally Robinson

Background to the problem

- Poor recognition of emotional and psychological abuse and neglect in research, policy and practice
- Existing research focuses largely on sexual and physical abuse
- Few people with intellectual disability asked about their abuse experiences
- Theoretical recognition of damaged identities, marginalisation and 'othering'

Research questions

- How do people with intellectual disability understand the experience of psychological and emotional abuse and neglect in disability accommodation services?
- What is the impact of that experience on them?
- What factors might predispose people to abuse, increase their risk and protect them against this form of abuse and neglect?

Research design – narrative collage

- Person with intellectual disability at the centre
 - Other supporters invited in to ‘bolster’ their narratives
 - Together, stories build a collage – gathering of collective experience
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- Traditional narrative and in depth interviews also used with other participants

Participants

- Four people with intellectual disability and their supporters built narrative collages
- Five family members, on behalf of people with high support needs developed narratives
= nine core narratives of people's 'service lives'
- Sixteen policy and advocacy stakeholder interviews

Results of the research

- 228 incidents of emotional and psychological abuse and neglect in people's 'service lives'
- All participants experienced multiple forms of abuse on multiple occasions
- Ranged from routine indignities to severe emotional trauma
- Creation of a 'climate of insult'

Examples from the narratives

- Tom had hurt his leg, and called his mother for advice. She suggested that he go to the hospital and get it checked. The support worker who was working with Tom that day said *'oh, I'm going home in a minute, I haven't got time to take you there'*, and pulled all the wires out of Tom's electric wheelchair, so he was unable to go. The worker left, leaving Tom lying on the floor, unable to leave the house. Tom said

He was training to be a doctor! And I told him his bedside manner... Sucked big time!

Tom's mum, Penny, said that the worker left the organisation, but was not disciplined, as far as she was aware.

- *You want to advocate for your child cause he's going to hospital, with his head split open every six weeks, but the service says 'no, you can't, the other mothers don't want anyone going to the house without an appointment'. So no mothers go to the house.*
- Rose, Jenny's mother

Sally Did you talk to Andrew about it [specific abuse problem Ann had raised]?

Ann Yeah, but he just rang them and, he just got the wrong side of the story. He just used to put me in the car and take me back.

Sally Right. And so after he called them, he didn't think that you were telling the truth?

Ann Mmm. Manipulative.

Sally Is that what he said?

Ann Mmm.

Themes emerging from the data

- The diffuse and pervasive nature of emotional and psychological abuse
- The damage done to people by thoughtless following of policy and practice by staff
- The damage done to their relationships with family and friends through the abuse
- The emotionally and psychologically abusive impact of poor quality care and the withholding of basic support and rights

- The emotional and psychological impact of punishment and control
- The emotional and psychological impact of living with threat and fear
- A lack of appropriate concern from services about harm suffered, and
- The failure of systemic abuse response mechanisms to protect people
- The ubiquitous place of power and control in this experience

Impact of the abuse

- People's capacity to develop and maintain healthy (particularly non-institutional) relationships
- Emotional and mental health – particularly depression and anxiety
- Ability to trust
- Cultural connections
- For family members – 'trade offs' in their quality of life in order to obtain quality support for their family member

Resistance and resilience

- All participants demonstrated great resilience – they are not passive victims.
- All had strategies for managing their emotions and distress, and had moved on with life in important ways.
- Lindemann Nelson's (2001) counterstories – repair of damaged identities
- Important to note that the abuse was (largely) in the past

Systemic issues

- The disability accommodation services system was predominantly top down, managerial, and procedurally driven – this impacted on recognition and response to emotional and psychological abuse and neglect
- Making complaints did not improve people's life circumstances, in the majority of cases

Influencing factors

- Predisposing – legislation, funding and policy for accommodation and support; quality assurance
- Risk – enforced co-residency; unresponsiveness at high policy levels; lack of protection in private residential sector
- Protective – involved presence of supporters; active community presence and relationships

Four key insights from this research:

1. The central place of systems

- The central place of systems in this form of abuse and neglect
 - » Creation of a climate in which ill treatment is expected
 - » No recognition of pattern or trend of abuse

- *Sustained* nature of emotional and psychological abuse is provided by the structural conditions of the service system

2. The cumulative impact

- The cumulative impact of emotional and psychological abuse and neglect over time
 - » Collage of insults and injuries
 - » Impact on participants emotional health and wellbeing
 - » Individual incidents of abuse should not be the only measurement

- Need to understand this form of abuse beyond individual incidents, in terms of peoples' 'service histories' and life histories

3. Recognition of abuse by those who experienced it

- Recognition of emotional and psychological abuse and neglect by people with intellectual disability
 - » Lack of abuse language does not equate to lack of understanding of wrong done

4. Lack of authority of people with intellectual disability

- The lack of moral authority accorded to people with intellectual disability in abuse acknowledgement and reporting
 - » Marginalisation and positioning of people with intellectual disability as 'other', less than human
 - » Professionalised explanations of abuse and neglect don't consider lived experience

The need for capacity building

- At a range of levels:
 - » Individual (resilience in people and families; skill in workers and supporters; education and training; advocacy; support services for victims)
 - » Systemic (moral & educative responses; increase policy focus; evaluation vs compliance monitoring; advocacy; energy & resources to respond to systemic causes)
 - » Structural (fragmentation of abuse landscape; 'higher order' issues; grassroots involvement in designing solutions; broadening the problem base)

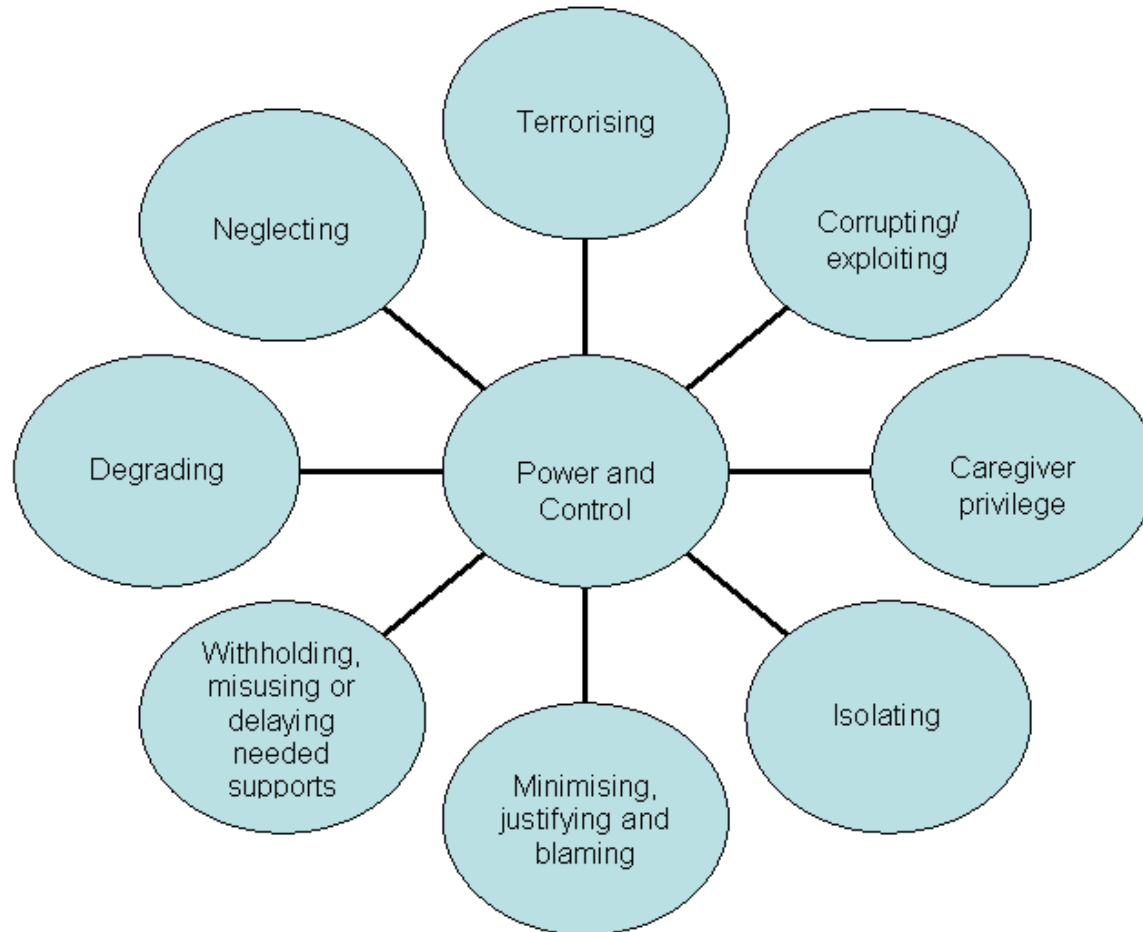
Underpinning all levels

- The creation and sustenance of protective factors – community based, individualised supported lifestyles with multiple relationships with unpaid people – demonstrated in the literature, and confirmed in this study to safeguard people against the experience of emotional and psychological abuse and neglect

Sally Robinson

s.robinson@griffith.edu.au

Understanding this form of abuse



Type of abuse	Number of references to the abuse in the interview data	Number of participants experiencing this form of abuse
<i>Caregiver privilege</i>	53	9
<i>Degrading</i>	34	9
<i>Isolating</i>	29	9
<i>Minimising, justifying and blaming</i>	35	9
<i>Neglecting</i>	25	8
<i>Terrorising</i>	36	7
<i>Withholding, misusing or delaying needed supports</i>	11	5
<i>Corrupting/exploiting</i>	5	3