

## Heart Hurt

Emotional and psychological abuse and neglect of people with intellectual disability

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### Aim of today's paper

- To share some of the early findings of the research
- To talk about the research approach that was taken
- To raise the issue of emotional and psychological abuse and neglect in this environment

### Research questions

- How do people with intellectual disability understand the experience of emotional and psychological abuse and neglect in disability accommodation services?
- What is the impact of that experience on them?

### Background to the research

- My background as a service provider and an advocate
- A concern that abuse research tends to go around people with disability – that they are not central to the research process
- A desire to know more about the lived experience of this sort of abuse and neglect

### Method of the research

- Narrative collage approach
- Snowball sampling
- 9 stories of people's 'service lives' – those parts of their past lives that intersected with formal disability accommodation support services. In depth interviews with:
  - 4 people who could tell their own stories (up to 3 interviews each)
  - 2 parents who also supported their adult children's stories
  - 1 support worker who also supported a person who told their own story
  - 5 family members who spoke on behalf of their adult family members who have high support needs
  - 14 other stakeholders, mainly policy and justice agency representatives

### Model of emotional and psychological abuse and neglect

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    graph TD
      PC((Power and Control)) --- T((Terrorizing))
      PC --- CE((Coercing and exploiting))
      PC --- I((Isolation))
      PC --- M((Minimizing, denying and blaming))
      PC --- W((Withholding resources or making needed supports))
      PC --- D((Degradation))
      PC --- H((Humiliation))
      T --- CE
      CE --- I
      I --- M
      M --- W
      W --- D
      D --- H
      H --- T
    
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What came out of this?

- An overwhelming volume and intensity of abuse and neglect
  - 251 incidents of emotional and psychological abuse and neglect identified among 9 people.
  - 147 incidents of other forms of abuse and neglect and crimes identified, such as theft, physical assault, sexual assault, chemical restraint, injury with unknown cause and inadequate staffing
    - Note – some of these were 'double counted', if two forms of abuse were contained in the one incident

Terrorising

- Coercing
- Threatening to hurt
- Frightening
- Intimidating
- Withholding basic support and rights
- Terminating relationship and leaving the person unattended
- Reporting non-compliance with a program
- Using more intrusive equipment
- Using consequences and punishments to gain compliant behaviour
- Pressuring the person to engage in fraud or other crimes

- Ivy says 'things got so bad at the centre, and I would say deliberately so, because they wanted us to want out people out. One mother told me she was told that in time to come, there would only be very violent men living at [institution], and she had a daughter. So that was some encouragement to move your daughter out of there!'

- Ann talks about sharing a room with a co-tenant who had epilepsy. She says 'And if she had been good and hadn't had a fit all week, she could go away for the weekend to her boyfriend's. I had to hold her tongue to she wouldn't get in trouble for having a fit. If I had've let it go and [she] had that fit, no weekend leave.'

Caregiver privilege

- Treating the person like a child or servant
- Making unilateral decisions
- Defining narrow, limiting roles and responsibilities
- Providing care in a way to accentuate the person's dependence and vulnerability
- Giving an opinion as if it were the person's own
- Denying the person the right to privacy
- Ignoring
- Discouraging
- Prohibiting the exercise of full capabilities

- Patrick used to visit his brother Dan in the rehab hospital, and try to stimulate him. A nurse said to him, "oh, it's alright for you, you come out here and spend a couple of hours' – it was more like six hours – 'and then go away and leave him and we have to deal with the [consequences]'. Because I would take him out walking along the fence and all sorts of other stuff to try and stimulate him. And you know, 'you're doing this and we've got to deal with the consequences'. And I said 'well, that's what you actually get paid for'.'

■ Jim said staff used to regularly go outside and have coffee together, and leave residents on their own. People used to cry and make so much noise that he couldn't watch TV, and he would go into his room to try and get some peace and quiet

**Degrading**

- Punishing or ridiculing
- Refusing to speak
- Ignoring requests
- Ignoring person
- Harassing
- Humiliating
- Ridiculing the person's culture, traditions, religion
- Ridiculing personal tastes
- Enforcing a negative reinforcement or behaviour program the person doesn't consent to

■ Amanda says 'There's so many different types of abuse, and it all comes down to the same thing. It's making people nothing. And Fran was nothing. There was never anything nice said about her, everything was negative. And she had to put up with that, and we had to put up with that, until we all sort of believed it, almost.'

■ Jim has a colostomy bag. In two services, he was punished when it came loose, once by a staff member who hit him when it came off, an once by a staff member who put him to bed in the afternoon if it came off.

**Minimising, justifying and blaming**

- Denying or making light of abuse
- Denying physical and emotional pain
- Justifying rules that limit autonomy, dignity and relationships for program's operational efficiency
- Excusing abuse as behaviour management
- Excusing abuse as caregiver stress
- Blaming the disability for the abuse
- Saying the person is not a 'good reporter' of abuse

■ Jim says 'I got my foot burnt one time, and I got in big trouble for it.... on the big motor at the front, at the back.' [exhaust pipe]

■ Rose says she has said to the staff in Jenny's current service that she thinks Jenny is depressed because she's not going anywhere exciting, and that their response is 'well, her life's better than other people's, so why should we worry about that?'

■ Kate says that in the place she volunteers, 'They control every part of people's life. When they get up, when they go to bed. Oh, they go for a rest at half past one, everybody lies down, they get up half past three, have a bath, have dinner, and go to bed at seven o'clock.'

**Isolating**

- Controlling access to friends, family and neighbours
- Controlling access to phone, TV, news
- Limiting employment possibilities because of caregiver schedule
- Discouraging contact with a person's case manager or advocate

- After a dispute with the facility, Patrick dropped his frequent visiting of Dan back to about once a fortnight. At a review, he told staff 'you know, I find it really sad that I can't come to visit someone I love because I can't deal with the institution where he lives.'
- An advocate talked about institution practices on entry, and a woman who had told her of her memory of 'crying because she wanted her mum, she had just been taken there and left there. And the workers were saying that they had a policy that it's better for them to get over the grieving process, and then you can visit. So, as long as she cried, she can't see them.'

- Tom lived in a hostel for six months which was up a flight of stairs. He relies on a wheelchair to get around. The only way for him to get out was for two people to carry him down the stairs. He very rarely went out.

**Withholding, misusing or delaying needed supports**

- Using medication to sedate the person for agency convenience
- Ignoring equipment safety requirements
- Breaking or not fixing adaptive equipment
- Refusing to use or destroying communication devices
- Withdrawing care or equipment to immobilise the person
- Using equipment to torture the person

- Jill was not provided with pureed food, although she had great difficulty eating, had a dysphagic disorder, and her weight dropped to dangerously low levels. Ivy says 'I always said she lived a life of misery and neglect, because your weight doesn't drop to 25 kilograms if you're being well cared for, does it?'

- Tom hurt his leg, and needed to get some medical attention. He says 'when I hurt my leg, I wanted to go to hospital. So, I rang my mum up, you know what I mean? I rang my mum up and said 'I hurt my leg'. She told me to get to the hospital. And the carer said, 'oh, I'm going home in a minute, I haven't got time to take you there'. The carer pulled the wires out of Tom's electric wheelchair, and left him lying on the floor, unable to get out of his house. Tom says 'He was training to be a doctor! And I told him his bedside manner... Sucked big time!'

Neglecting

- Failing to provide nurturance
- Failing to provide stimulation

- Patrick describes Dan being housed on the side of the facility which is for people with the highest support needs, where there is little stimulation, even though he was able to communicate in many ways. He feels the staff failed to provide him with physical therapy and also with emotional and psychological therapy and stimulation. He says 'So, there was a lot of neglect, I think in that time he'd just roam the corridors, you know, his 'peek a boo, skiddly on doo' chant just became stronger and stronger.'

- Kate is working on a voluntary basis on a communication program with a lady with high support needs. Staff have no means of communication with this lady. She made a breakthrough with the lady, who blinked once for yes when asked did she want a drink, but staff took her away before the drink could be given.

Corrupting/exploiting

- Socialising a person into accepting ideas or behaviour which oppose legal standards
- Using a person for advantage or profit
- Training a person to serve in the interests of the abuser

- Tom's mum says 'you'd think Tom was working for them, rather than those workers working for him'
- In her current living environment, Rose feels that staff manage Jenny by 'getting her to be quiet, or go to her room, or do stuff they want done, so it makes it easier for them'
- In her previous living arrangement, Rose feels that a male worker actively worked to turn Jenny's co-tenant Bruce against her, the thus encourage her to leave the house, by continually making anti-female statements and inciting Bruce to make life difficult for Jenny and also for female staff.

### But, despite all this...

- People also talked about
  - Relationships and how they can be protective
  - Moving on in life (from the abusive situations)
  - Appreciating current good living situations
  - The importance of having supporters in your life

### Some very early conclusions

- This form of abuse is frequently about relationships
- It is often long term, and often cumulative
- It has significant negative impacts on people's lives long term
- It can be non-intentional on the part of the abuser
- It can be systemic in form, but emotional in the way that it is received
- It is very prevalent in formal disability services
- It is not well recognised

### In conclusion

- This research is not complete
- So far, the intensity and volume of abuses experienced makes it clear that this is a critical issue for our field to address
- Our current understanding of abuse as a single incident, addressable through linear complaints processes, may not adequately address some of the very complex causative factors behind this form of abuse and neglect

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