

Health care for people with cognitive disability

People with intellectual disability said medical professionals discriminated against them. They said their family members were often expected to speak for them.

Tim, 20, said:

‘The medical system just needs to stop being so stringent ... because they just presume ... they won’t actually respect you as a person. They expect the person that with you to answer all the questions when the person that has the disability is right there.

‘When I fractured my knee last year I was stuck in a wheelchair for a couple of weeks, so I couldn’t physically walk for a little while ... And when I went to the hospital for the first time the medical professionals did not look at me in the eye because they had my personal profile in their hand and they saw the word autism and they looked at my dad and asked him everything from my name to, you know, what school I went to — yadda, yadda, yadda — and then when he went to my school information I was like ... “Excuse me! I’m right here in front of you. Ask me the questions.”’

Luke said he often had to explain his disability to doctors because it was ‘so rare’.

Eileen receives healthcare from an Aboriginal community health centre. She said she often took a case worker with her for gynaecological check-ups because of a history of abuse.

Families reported being lied to by health care professionals.

Miranda died at the age of 42.

Her parents, Ewan and Evelyn, said her premature death was caused by the misconduct of her doctors.

Miranda was born with Down syndrome in 1972. Like many children with Down syndrome, she had a heart condition. In most cases, those heart conditions can be corrected with surgery.

In Miranda’s case there wasn’t any corrective surgery because her doctors did not tell Ewan and Evelyn that there was a problem. Instead, when they took their infant daughter to the hospital their doctor treated her ailments — Miranda had pneumonia 13 times during her life — and told her parents to take her home and ‘make a pet of her.’

‘He just lied,’ Ewan said of the doctor.

'We've had this experience with medical practitioners not telling you something — thinking a sentence of death is a good idea,' Evelyn said. 'The medical practitioners did a disservice to her by not saying she had a heart defect. They really hid that.'

The family moved to Adelaide when Miranda was 5 years old. That was when they found out, from their new doctors, about their daughter's heart defect — and that it was too late for corrective surgery.

Advocates said that the behaviour of some medical professionals towards people with intellectual disability pointed to a chronic lack of training, as well as an assumption that people with intellectual disability were not able to give consent. They also spoke of cases where people with intellectual disability were medicated for non-medical reasons.

One advocate, Amanda, said:

'We've just run some workshops for one of the hospitals here. ... They have had some patients with intellectual disability and limited ability to be able to communicate and we were really surprised at things that we thought would just be basic practice went happening. Like when the person was admitted. They come, the hospital wasn't given like their positive behaviour support plan, which, you know, was critical for them being able to be consistent in their approach with that person. And, so, they were definitely seeing some challenging behaviour from that person, but the hospital staff didn't seem to be aware that that should be something that they should ask for. ... Those kinds of things can often restrict people's rights being respected, so they're not treated as fairly as someone without a disability because that information hasn't been passed on.'

Sophie, an advocate who has worked in disability care, said doctors medicated people with intellectual disability for non-medical reasons.

'They've had a general anaesthetic administered in order to get a teeth cleaning. ... The other big thing that I've always noticed myself is the assumption [by doctors] that a person can't consent or understand for themselves, rather than assuming that they are able to and then sort of being corrected if the case is otherwise. The assumption is always that a person needs somebody to make a decision for them. ... There doesn't just seem to be that mainstream knowledge that people are people.'

Sophie said had supported a man with Down syndrome who did not like having his haircut or nails trimmed. A doctor's solution to the issue was to prescribe Midazolam.

Sophie said:

'The doctor, happily, without asking too many questions prescribed him to have Midazolam administered to knock him out completely, and he would wake up half an hour later with his hair cut and his nails cut ... by support workers. So, before he went to work that day, he would be sedated along with his coffee and then he would wake up shorn like a sheep.'

What would he do when he woke?

Sophie: 'He would be upset. ... I would assume that he felt violated.'

In another case, Sophie spoke of an incident when a dentist took extreme measures to treat the resident of an institution.

She said:

'They also have their own in-house dentist so all the people that lived in this institution got their dental care done on campus. In some ways he [the dentist] was fantastic. If the client didn't want to get out of the car, he would come out and he would do a check-up in the car seat. But there were other times ... I just thought of a time we had a person who kept punching himself in the face, so we took him to the dentist, and they worked out he had a big abscess on his tooth. And he wasn't happy to be at the dentist. And the dentist said, "Right. Now we've got to hold him down and pull the tooth out or we call an ambulance and he is going to go to hospital for three days."

The dentist gave the patient a local anaesthetic, then he was held down and his tooth extracted.

Case Study: Press the buzzer for help

This is the story of a group home resident who was taken to hospital, left unattended and moved to a palliative ward. She survived.

Carly lives in a group home and requires around-the-clock care.

A few years ago, she had a medical emergency and was taken to hospital.

Carly's support workers left her at the hospital. They didn't call her family.

Carly, who doesn't use words to communicate and is unable to move her hands, spent the night in hospital without any support.

Carly's cousin and advocate, Angela, drove four hours to the hospital as soon as she was told of the hospitalization. When she arrived, Angela was shocked when she heard a nurse tell Carly to ring the buzzer if she needed assistance.

Angela said:

'It's physically impossible for her to ring a buzzer! So, when I went and complained about it, they put a baby monitor in the room.'

To make matters worse, during her first night in hospital – when she had no support – Carly was given medication that thinned out her mucus, placing her at risk of aspiration, and moved to a palliative care ward.

'I'm surprised it didn't kill her,' Angela said. 'And nobody rang me when they left her at the emergency department. ... She wasn't even outside the nurses' station; she was down the hall.'

Later, after Angela complained, the group home sent support staff to help at mealtimes.

Carly still lives in the group home.