

Restrictive Practices

Family members were pragmatic on the subject of restrictive practices. They wanted restrictive practices monitored and minimised — even eliminated — but were concerned by the broad definition of the term ‘restrictive practice’. They wanted a greater oversight of extreme practices and more support to improve individual quality of life.

Jane lives with her adult daughter, Ava, who has an intellectual disability.

She said the definition of restrictive practice needed to be ‘more balanced and defined’.

‘Restrictive practices are overbearing, but there is also overbearing oversight of minor practices,’ she said, giving the example of a parent who was not allowed to use a seatbelt for a wheelchair that was used to keep their child from being thrown from the chair during a seizure.

‘I think restrictive practices should be eliminated,’ Jane said, ‘but I need people to look over what is a restrictive practice.’

Advocates and disability services workers had concerns about the use, reporting and investigation of restrictive practices. They said staff often did not understand the definition of restrictive practices. They said the definitions of restrictive practices varied between jurisdictions. They said the reporting mechanisms were too bureaucratic and time consuming, which increased the likelihood that families would not report. And they said the NDIS Quality and Safeguards Commission was a ‘toothless tiger’ because it was not proactive, was not independent of the Federal Minister for the NDIS and lacked the resources to inspect or investigate. In Victoria, advocates reported a new trend that sounded like a throwback to the medical model, with some psychologists and psychiatrists using mental health diagnoses as cover for the use of chemical restraints.

Brian is an advocate. He said he had a ‘feeling of unease’ about the NDIS Quality and Safeguards Commission:

‘I hear anecdotal complaints about it as just being, you know, yet another bureaucracy that's very focused on systems and data and not very responsive to individual circumstances. ... With restrictive practices, you know, their main focus seems to be on getting reporting of what's happening and ensuring that there is a behaviour support plan in place. That doesn't tell me much at all about what's really happening in the life of that person. ... You can have the best behaviour support plan in the world. ... To what degree it's actually being implemented at the coalface is another matter altogether.’

Brian said that the legislation establishing the Quality and Safeguards Commission needed to be amended to strengthen the Commission’s independence:

‘The legislation establishing it says that it's subject to the direction of the Minister ... except in relation to individual cases. So, that gives enormous sort of scope for political interference and for it to ... keep the Minister happy as opposed to being a fearless watchdog.’

He said the legislation governing the NSW Ageing and Disability Commission, which has a similar role to the NDIS Quality and Safeguards Commission, had been amended to give the Commissioner more control over the direction of investigations.

The Commonwealth, he said, could easily follow the lead of NSW.

Stephen is an advocate.

Recently, he visited more than 60 disability service sites and asked the staff whether they knew their employer's restrictive practices policy. 'I didn't meet one staff member who knew the restrictive practices policy of their organisation,' he said.

'I went to this one house and they'd put up a fence so that people couldn't get into the kitchen and, in guiding rather than scolding mode, I said to the supervisor, I said, "You understand that that fence is a restrictive practice." And they said, "No, it's not. It's just a fence to keep people out of the kitchen." ... There's been a significant emphasis in the use of restrictive practices ... but many of the locks on refrigerators were basically so people couldn't get into the fridge and spill the milk.'

Lisa is an academic and advocate.

She said:

'Challenging behaviours are often connected to a chronic health issue that had not been identified. If you can communicate then people with disability are less likely to have to act out.'

Lisa cited the case of a non-verbal man, now in his late 20s, who had been categorised as problematic in school. After leaving school, his family established a communication system — and he started telling them about the underlying issues that were causing his behavioural escalations. As a result, his family began to deal with the underlying issues and systematically remove his restrictive practices.

Lisa said:

'We keep seeing behaviour-based programs and they're not addressing communication.'

Anna works in disability services.

She said restrictive practices were overused because most staff lacked the training and expertise required to work with clients with complex support needs.

She said that many staff members didn't understand what a restrictive practice was, and many disability services weren't reporting restrictive practices.

Lillian is an advocate.

She said the reporting requirements were too cumbersome. She was concerned families were 'going underground' to avoid reporting the use of restrictive practices on a person with disability.

She said many of the issues with the overuse of restrictive practices were connected to the disability sector's inability to cater to the needs of clients with complex support needs.

Lillian said:

'It's really hard to actually engage providers to work with people who ...they're kind of going, "Actually, it's too hard, and it's not cost effective."'

She said the inability of the system to deal with people with complex support needs pushed many families into extreme situations. Families try to muddle through on their own, self-managing, but if something goes wrong, they end up with their child under state care. If the family or participant are seen to be troublemakers, the family bounces from one service provider to another.

Part of the danger, Lillian said, was that disability services operated by state and territory governments used to be the 'provider of last resort' for families in crisis, but, under the NDIS model, the last resort had become hospital emergency departments.

She said:

'But there's only a few [hospital] beds and they're meant to be transitional until ... accommodation is sourced, but I think people are kind of getting stuck. And it's a thin market of people who are actually qualified to do this kind of work with support workers and behaviour support practitioners.'

Sophie, an advocate, said:

'My understanding has always been that you have to try every single other thing first and then, worst case scenario, everything failing, you can use this restrictive practice until we find something better. But if people are only funded once a year for one load of intervention for positive behaviour supports, there's no way that's going to happen.'

Hannah is an advocate.

She said there was an urgent need to set a nationally consistent framework governing the use of restrictive practices.

'Principles need to be debated and set,' she said. 'For instance, at what age can you lock up a child in an adult setting? It's easier to get a restrictive practice put in place than it is to get the resources that can be dedicated to work out and put appropriate supports in place [to deal with the underlying issues that are driving extreme behaviours].'

Hannah was also concerned that some states, such as Tasmania, did not have enough protections, such as community visitor programs, in place to protect people with disability from abuses.

Vicky is an advocate.

She said:

'Positive behaviour support ... that's the best way to reduce and eliminate restrictive practices. As far as what groups are vulnerable, I would say in my experience where there is two or three people that live in the same [group] home ... and it wasn't their choice, inevitably restrictive practices are brought into the home to make it easier for the staff. ... People with intellectual disabilities are particularly vulnerable to restrictive practices.'

To illustrate the vulnerability of people with intellectual disabilities, Vicky spoke of the recent case of a man who was, she said, left to die in an aged care facility. The man, who had an intellectual disability and self-harmed, had spent his life in State-run group homes. At the age of 64, he was moved to residential aged care. In the aged care facility, he was drugged and locked in his room because 'they were so short staffed'.

Vicky said:

'There's always a reason for behaviour – always a reason for behaviour. You take away triggers. Give someone a really good quality of life where they are happy in their life and you're just reducing the risk of them to display any harmful behaviours. ... It's best practice around the globe, and if you do it well, it works.'

Donald is an advocate.

He said a new trend was emerging:

'There seem to be more psychologists now or psychiatrists who are being called on to diagnose or to assess behaviours of concern and they're prepared to call it – particularly for people with autism – categorize that as a mental health issue rather than a behavioural issue. And once you go into that model then they avoid the same sorts of safeguards that are there through the senior practitioner. ... So, this use of medications to deal with behaviour is just a complete reversal of everything we fought for the last 30 years and I can just see it's going to lead to more people just being put back in those corners and medicated out of their heads. That's the other reason why we need a NDIS Commission with independent statutory power and with the resources to actually ensure that the workforce is trying to actually implement behaviour plans ... and actually teach people to support people within those plans. ...

'Whoever has the power to apply the label that describes who they are and what they are. Whoever has got the power to apply that lens, very quickly becomes an empire, and there's all these vested interests that all fall in behind it. And the person who is the subject of it's got no power at all. We see this deconstructing – this dedifferentiation – of disability. And people might think, "Yeah, that's good because we're all human beings, et cetera." But what it really does, that

plays into the bean counters' hands, who just say, "We don't need to do specialist things. Everybody can just be treated the same." ...

'The cohort that comes to my mind immediately is people with intellectual disability and autism. And the reason that they are so susceptible ...is they can really challenge people's skills. They can challenge routines. And any response to something that's annoying is to try and shut it up or to put it down. And so, when people were back in the institutions, it was easy; you just threw a cup full of meds into them. Or you'd do what they used to do at Mayday Hills and you just throw all their medications into their meals. No individual medications — they were all on the same things — and chuck it into this big pig bowl and just dish it out. It was like something out of *One Flew Over the Cuckoo's Nest*. That's what it was. When people were in institutions, that's exactly what happened. My early experiences of going into institutions and trying to support or help people who are just sitting in corners, rocking back and forth, rocking back and forth — out of their brains, basically.'

Case Study: A life in shackles

This is the story of a man in his 30s.

Adam has been in the disability system since he was a child.

His advocate, Clare, said he was the victim of the worst restrictive practices she had seen. The biography of Adam is what Clare calls 'folklore' because disability files are archived every 12 months. As a consequence, the official story of what happened during his childhood and early adulthood is buried.

Clare said:

'What I've been told is – by staff who've known him for a really long time – is that he was sent away to a residential school as a child and they had him chained to the floor. They put bolts in the floor to chain him to. ... He landed in one of Victoria's disability institutions as a young person and what I've heard is that he was restrained with in handcuffs for up to 23 hours a day, and that those restraints have caused his shoulder cuffs to basically rust downwards, which has also made him hyper anxious — because he's been subjected to many takedowns by staff — and his response to the world now is hyper vigilance. And, if in any way made anxious, hyper violent.'

Adam lives alone in a secure unit. He has one service provider: 24 hours a day, 7 days a week.

'I went into his home,' Clare said. 'It is not a place you would want to live, someplace anyone would want to live. It's dilapidated, it's depressing. He's been there a long time, and it's overlooked by the institution that he previously lived in. ... He is captive.'

Since 2016, Clare has advocated for the NDIS to include a goal in Adam's plan 'to explore housing options' so that he at least has the opportunity to have some choices about where he would like to live.

Clare said:

'And because I don't have a formal role and because the NDIS doesn't recognise advocates anywhere on their system as having any legitimate role — we do not exist in their system as an entity at all — I have no possible way of contesting that a goal should have gone in the plan because what right do I have to say that he should have the chance to consider other options. And my question is: what right does anyone else have to say that he should not?

'The weight at the moment leans in the favour of keeping things how they are because anything else would be a decision, and that's how people's rights become meaningless. He has a right to look for other options, but I could not get a goal in the plan. Not in the first or second [NDIS] plan could I get that housing goal in there even though I specifically asked and everyone at the meeting agreed that it should happen. And in the third plan I said to the planner, "You will be putting a goal in there that says that he is going to be looking around." And she said, "I think that we would need a guardian for that." And I said, "It's not a decision to have options put in front of you."

'I also asked for independent support for decision making, I asked for the funding of an independent facilitator from a registered NDIS service provider to develop a circle of support

made up of volunteers who would be willing to start exploring what his will and preferences look like within a framework — within a proper framework. “No.” “Why not? Why not?” “Because it’s a duplication of supports.” “How is it a duplication of supports?” “Because we funded support coordination.” I said, “The support coordinator would have a conflict of interest if they were facilitating the decision-making circle, don’t you think?” A support coordinator is supposed to take the person’s direction. And she said, “Well, then he needs a guardian.” And they will not fund independent support for decision-making. And I have asked for multiple [NDIS] participants who have no family, maybe one provider, maybe a day program and one provider; no one else to advocate for them and literally, absolutely zero capacity to find their way out of these systems. Zero capacity to find their way out ... and I cannot get the NDIA to fund support for decision making.’

Adam’s latest NDIS plan includes the option to explore other housing options but support for decision-making was denied. He still lives in the shadow of the institution where he was restrained for up to 23 hours a day.

‘It’s an extreme example,’ Clare said, ‘but everything springs from there.’