

## **‘Unattractive consumers’**

*This story encapsulates the systemic failings of governments in general and the disability sector in particular — and shows how those failings, which are effectively systemic abuse, endanger the lives of people with intellectual disability and their families.*

Peter is 13. He spent the first three years of his life battling brain cancer.

His mother, Dawn, said:

‘Up until the age of three he was pretty much under the umbrella of the oncology team, and that’s kind of like the Ferrari of health care. It’s team led. It is comprehensive, multidisciplinary. It’s well resourced. It’s really the model of care that we need for disability management, too.’

Peter recovered from cancer but acquired a brain injury and hearing and vision loss during treatment. He has spent the past decade bouncing around the disability system.

*Three years in a Ferrari health system. How would you characterise the 10 years since in the disability system?*

Dawn: ‘Sort of a Datsun with a flat tire. ... The lack of ownership [by professionals in the system] is really, really awful.’

If anything, Dawn’s remark is an understatement. The system was more than ‘awful’ for Peter and his family. Over the past decade they have been systemically abused — categorised as a complex case and therefore left to their own devices to cope with untreated chronic health conditions, a lack of services coordination and minimal respite.

In the end, this systemic neglect led to Peter’s younger brother, Xavier, attempting suicide.

### **Professional negligence**

It’s important to unpack the systemic neglect of Peter, step by step.

When Peter was 3 years old, he was diagnosed as autistic. His parents — both of whom are medical professionals — believe this was a misdiagnosis.

Dawn said:

‘They slapped an autism label on him at three because communication wasn’t working and behaviour was off and, you know, there was a delay and the triage of diagnosis says that that’s actually autism, where it’s actually brain injury, I believe ... there might be another possibility that there’s some underlying pathology.’

By the time Peter was 7 years old, undiagnosed health problems caused by his cancer treatment radically changed his behaviour. He became ‘very violent’, Dawn said, putting his head through nine windows in six months. In the end, Dawn was forced to take Peter to the local hospital for help diagnosing the cause of his change in behaviour, but the hospital didn’t help.

Dawn said:

'We were told after waiting eight hours that no one would be coming because it was neither neurology nor oncology, so we'd have to go home, at which point the psychiatrist, who we saw in the community ... managed to do a deal with someone working at the hospital to get us admitted over the course of the weekend. We were told to call an ambulance if things escalated.

'So, we were admitted as a psych patient, that's the only way we could get into the hospital, as a psych patient for a week, and he was sedated to his eyeballs and nobody came to examine this child until I insisted we weren't leaving until he was examined and someone [after five days in hospital] sent a junior registrar down to do a cursory look over him and couldn't find anything wrong. We were discharged.'

Two weeks after the hospital stay, Peter's face ballooned.

Dawn said:

'He had three septic teeth. Then they operated on it as an emergency and we were discharged and six weeks later the face started to get red and painful again and the behaviour started to escalate and I wrote to the specialist, the dentist, and said, "Like, I think we still got this problem," and she sent me this message back and said, "Well, you know what, these kids get these problems."'

Dawn sighed as she remembered the dentist's dismissal of Peter's suffering. She said the three teeth that caused his violent behaviour were black and crumbling when they were extracted.

Peter spent the next year bouncing between dentists and specialists. He is now 13 years old and has chronic dental problems. Dawn said Peter's behaviour escalated whenever he was in pain. When that happened, Dawn locked herself in a room with Peter's 11-year-old brother, Xavier. She said:

'If he's really kicking off ... we'll lock ourselves in his [Xavier's] room until things have calmed down a bit, because we've, we've pretty much set up the place so that we can remove ourselves and he can't do too much damage and he's safe — you know what I mean? But we can't, certainly can't, lock him away, and I wouldn't want to, but we actually need to be able to remove ourselves if there's a problem. ...

'Two weeks ago, they had to call the police because my husband was working and he [Peter] had me by the throat. He smashed my head into the wall, but he was holding his face. And, you know, Nurofen and Panadol used to work quite well with him, but it's becoming less and less effective. ...

'It goes from zero to 10 very quickly. I mean, he does have a frontal-lobe injury ... [but] we will have weeks where he's really good. Like, just beautiful. And he'll be singing and happy and joyful and there won't be any single incident. And then we'll go into this frenzied — like, attacks on people where we need two big male support workers to take him out for community access. ... It's such a change, an extreme change in the child, and it always coincides with holding his face and waking up in the middle of the night.'

## **Lack of training**

For Dawn, managing her son's medical appointments has become a full-time job, including multiple visits to hospital emergency departments.

She said:

'It's happened to us a few times where we've just been put in a waiting room waiting for a specialist for hours at a time with him physical and the doctor will come and will push his computer on a little trolley to take a history, but he'll stand between us and the door with his back out the door so he doesn't get hurt. But they're happy to leave me there on my own with this child who's belting me. How can you say that that's okay in terms of health intervention?

'I think there's the presumption that it's not pain and suffering. It's behaviour. Even though you can say to them, "This is not what he is usually like and this is an escalation in his behaviour." ... I come from a nursing background. My husband's a doctor. I know that sometimes you don't have the answers to manage this. And I know, certainly in nursing training, they don't have any training, disability training, anymore. We used to have specialist disability nurses and they would go down a disability stream of education. ... The under-skilling of nursing and health care professionals in these situations is really obvious. ...

'The frustration for us over this whole process is the lack of ownership and the lack of team coordination. Yeah, it's like the buck stops with nobody.'

What you're talking about, then, is really a sink-or-swim system of healthcare for your son?

Dawn: 'Yes. ... And going forward it's going to be harder and harder to manage that because he is quite physical and you know, in some of my reading I came across his awful turn of phrase that stuck with me forever, but I think it probably, you know, probably reflects the attitude — "unattractive health care consumers". ... They are time consuming, they're expensive and they're difficult to manage and difficult to get a resolution out of, and I think that's where someone needs to have a really good look at how we deliver health care, because it serves no one well if people are developing chronic illness because of neglect. ... What I think would be really important, and I think it would probably eventually be cost effective to the government, was actually: each person with a complex disability falls under the management of a team and that team will manage that person from, you know, their childhood, too.'

Currently, Dawn said people with disability fall through the system's cracks unless they have the support of a strong family or advocates:

'It's up to the parents to push really hard. ... I just always worry about the people who are too tired or don't have the language skills or English skills or can't be bothered. Or a single mum with two or three kids on the [autism] spectrum. How are those people managing? ... It's kind of almost an elitist thing. ... If you don't fight hard in your corner, that person will rot.'

## **Restrictive practices**

The system's bureaucratic methods make life much harder. For example, Dawn said, documenting the restrictive practices required to manage her son's escalating behaviour required multiple interactions with doctors, specialists, and panels:

'We're really struggling with our behaviour clinician at the moment. He's not really available. ... He was due to redo our behaviour support plan ... and he's gone on leave without it finished.'

As a consequence, Peter had not been able to have a break away from home for a year.

Dawn said:

'We had an incident report two weeks ago where – we've got a dog and [Peter] went to sit on the dog and the support worker redirected him ... and put in an incident report, mistakenly thinking

that's what you had to do. And then we had calls from the [NDIS] Quality and Safeguards Commission. We all had to do an hour-long sort of interview about what restraints were in place, even though it became very quickly clear that... he was just redirected. And we've since put a thing together about the difference between restrictive practice and redirection.

'We do get a lot of it. ... It's incredibly time consuming ... and I feel like while we're doing the right thing, putting in the paperwork, [and] that the other people that aren't even doing the paperwork and just not bothering. We're the conscientious ones. It's the ones they never hear from [that the Quality and Safeguards Commission should worry about]. ...

'The paperwork's extraordinary. And, so, if you change a restrictive practice, ... the restrictive behaviour support clinician has to rewrite the behaviour support plan. We have to go to the GP, get the GP to write to the school or any other providers he's in contact with. We have to write all the different medication forms for each of those providers from the GP. And then we have to submit it to the Quality and Safeguards Commission, who then review it and approve it.'

Dawn said Peter's behaviour required changes to his medication every three weeks. That meant that she had to navigate a paper storm every three weeks to get her son's updated behaviour support plan approved by the Quality and Safeguards Commission.

'I just spend hours doing it. I spend my life doing it,' she said.

## **COVID-19**

Peter's school has been very supportive. Dawn said that the school community, which has lost families to suicide, provided him with constant support in the classroom and the playground:

'Last year he smashed one of the teacher's head into the wall and she was off with concussion for a week. And you know I always feel very grateful that he still has a space there and that they've been able to manage. ... We've really hit the education jackpot at that school.'

The COVID-19 lockdown disrupted Peter's support network, with the family losing support workers. Dawn said that the loss of a support worker was difficult because the only time Peter had a break was when he was attending school or on an outing:

'We don't actually have out-of-home respite. It [respite] is when the workers will take [Peter] on a train into the city or will go somewhere out.'

Dawn said Peter was rejected for out-of-home respite care because of his complex needs. 'The family is constantly knocked back for respite, because the services don't want challenging kids,' she said.

In other words, services are set up in such a way that they do not help the families most in need. Dawn said there was an urgent need for support for people with complex support needs because 'then you could hope for a little bit more than they come back alive and they haven't been abused, which is the kind of thinking at the moment. ... If we had really good rest ... then that would, that would be a good thing. We actually got a really big [NDIS] package this time because last time I took it to the media ... but you can't buy the services.'

In the meantime, Dawn said, she used her spare time to fight for systemic reform:

'You can fight your own corner for your own child, but you kind of have to fight the bigger fight because there's other people who don't have the fight left in them anymore.'