

# Living Library - NDTi

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## Kirsten's Story

Yeah, 'cause, I mean that the psychologist that Tom had when he was in the medium secure hospital, he was the first person who took the time to get to know Tom and got to know me as well.

Rather than looking at what was on a piece written on a piece of paper about him and about us.

**“Autistic adults really are just  
expected to get on with it.”**

So, his approach was quite different because he wanted to know not just about who Tom was then and there, but about everything that led him up to that point to really get inside, sort of how he thought and felt about things. He also did some family therapy sessions with me and Tom because obviously, the incident that had led to him being admitted was when he strangled me and and wanted to kill me. No one had ever actually even really addressed that or addressed the trauma

that I felt when that happened and the kind of conflict that it put in me as a mother, but also as a victim.

And I think it was only at that point that I realised, as a mum, that he wasn't going to ever be coming home to me, that our relationship, whatever it would be in the future, would never be the same again.

And he was only very young. He's only, you know, he was 14 when he went into hospital and nearly 17 by the time he came out. It was just before his 17th birthday. And that sort of led me to think about, OK, well, what does that future mean? What does that future look like? I think without that psychologist I wouldn't have been able to consider the option of Tom living independently. I would just wanted him to come home.

Where's he going to go? How's he going to live?

But then at the same time trying to see it as a positive thing, as in this is a real opportunity for Tom to be independent and to have the support he needs to be independent. Because I never wanted him to be institutionalised or overly dependent on me, I wanted him to have all the things in his life that he wanted for himself and that didn't involve, you know, being stuck at home with me for the rest of his life.

I knew he wanted a career and his own place and independence. And so, it was really thinking about, OK, how do we achieve that from sitting in a medium secure hospital. It seemed overwhelming.

But that's when I was very lucky to get involved with Orbis. The small supports organisation.

Realistically, I didn't have many options because on paper Tom's profile was such that I mean, he was he was just described as a dangerous.

Young person and he had this hefty reputation for what he'd done to me, but also what he'd done when he was in hospital to himself and members of staff and other patients.

Again, Orbis totally went into bat for me because they weren't listening to me. Community services and teams had never listened to me, which is kind of the problem in the first place.

But then I had, I had this partner in crime. Now I had the head of Orbis, who was going into meetings with me, saying, you know, no, that's not the way it's going to work. This is the way it's going to work. And we can do this. And this is the way we've done it for other people.

And we can really make it work. So that gave me a lot of confidence, and Orbis stepped in. When the community teams failed. They failed with his accommodation; they made false promises which really could have knocked his discharge from hospital back. But again, Orbis stepped in. They went looking out for privately rented accommodation. Nigel himself went guarantor on Tom's tenancy because he was too young to have a tenancy without a guarantor.

Set up his staff team, he chose his own staff team. He interviewed his staff team. It was very clear that they are not a risk-averse organisation. They will put in support where it's needed but withdraw support where it's not. And I think after Tom being in a medium secure hospital, he really needed to feel that he wasn't over supported.

But he had choice and control, and he had his freedom. So, it looked and felt nothing like hospital, even though there were people with him all the time, they weren't in his face.

And I think that made a really big difference to him. And then obviously it boosted my confidence because I was, you know, so scared particularly in those first few weeks about what could happen.

The psychologist and Nigel are kind of specialists in their field. They really understand and know what's likely to happen? How the other person may feel? But more than that, they actually care. They're actually interested in people. They actually show, you know, commitment and caring. Most of the people that we encountered in services didn't show caring or interest in either me or Tom.

He would be treated in a particular way. Every appointment we went to, every person he met, and it still happens. He said he said, 'mum they put on that funny voice.'

It's really, really patronising. They are not relaxed; they're not even coming across as human beings. They're coming across as if they're handling something and there's no genuine regard. It's like to them, the person is removed. They are handling a 'thing.' And both Tom and I hate it, but I know he hates it much more than I do because it's really directed at him. You know? It's like it's almost like when they say about British people abroad. Rather than bothering to learn the language, they just talk slower and louder. That's what it feels like trying to communicate with services about my autistic son, and I think for him it just puts a huge barrier between him and the rest of the world.

It's almost like you must completely subsume yourself. You can't be yourself because you're asking for something. You must be lower than the other person. It's like a conversation that starts off where you're going, cap in hand, and then it becomes about compliance. Who's compliant, who's not compliant. You have to say the things they want to hear. You have to work out what it is they want you to say. Because ultimately, you're asking them for something that you desperately need

and can't get on your own. It's awful to need help to live your life, to exist. But rather than that being done in a caring way.

this othering and this kind of lack of respect. It's humiliating and it's incredibly frustrating because more often than not, the computer says no.

You're asking for help to in the way to support you to live your life the way you have to live it, because it's not like Tom has a choice.

And then when that answer is, well, we don't do things like that. We don't do it that way. It tells you again that you're wrong and that you don't fit and you don't work.

And you're annoying and frustrate other people just because of who you are.

It sends a message, and I would say it's been sending me this message subliminally over the 21 years he's been alive, that his life has no value or meaning, and we'd much rather he wasn't on the planet.

I mean, he's at the point now where he just wants to leave the area, he wants to go somewhere completely different.

Because he doesn't feel that he can be anything other than the person he's described as in those notes.

You don't have the same rights and freedoms as everyone else, and you're not worthy of the same treatments and freedoms as everyone else. You've just got to be grateful for what you've got. Stay in the place we put you, be happy with what you get and make it work.

And if you don't do that, you're ungrateful and you get nothing.

Well, my life is just waiting for the phone call.

And I feel as a mother that I have totally failed.

And that I am at some point going to lose him and.

That there is I. I just feel that I've never done enough because I can't make the world right. I can't get him the things that he needs and I'm absolutely exhausted and worn out. I've given him

everything I've got and to feel as a mother that everything you've got is not enough and you might lose your child because of that.

It's indescribably painful. Because he was doing so well. And he turned 18.

And he then, of course, the dynamic completely changed because he was making the decisions, which I fully support his right to make decisions. It's all part of independence and his rights. And I don't believe that I should have a role in anything other than supporting him in the way he needs. I have no right to direct his life. And I talk a lot actually with people when I talk about human rights, I talk about the right to make unwise decisions because I think that's so important.

Yeah, I think that's the biggest difference for me between child services and adult services, adult services will just walk away.

He'll just walk away. They won't follow up. They won't check.

I mean, in some cases it comes down to diagnostic criteria. You know, I think Tom has suffered because he's autistic without a learning disability and services tend to be set up for learning disabilities rather than autism.

Autistic adults really are just expected to get on with it.

And they're either, you know, assumed to be incapable and treated as if they are incapable so that they can access support.

Or they get nothing until these crises happen. And I would sort of use Alexis Quinn as a very good example of this. Yes, she functions very well, but then, you know, there was a death in her family and that sent her reeling. And she just needed help and support around a bereavement.

And because that wasn't there, she ended up in hospital and all of the terrible things that happened to her because things happen in life.

And when they do and it's like, Tom, there was an incident at college, and they treated him really badly after that. And now he is out of education completely and I think he has a fear of ever going back into education so that is basically halted his future completely.