

# #7 The frustration of negotiating services

Many of the storytellers talked of the difficulties they faced when trying to access services or negotiate care across services. One of the stories in particular, told to us by a woman about her son's care, demonstrates how inappropriate care and difficulties accessing services can cause distress both to the service user and to the person who cares for them.

This storyteller described a series of difficult experiences trying to secure appropriate care for her son, who has both Asperger's syndrome and bipolar disorder. She described experiences with services that were very mixed.

At the outset, she spoke with high regard for her son's care co-ordinator and Early Intervention in Psychosis services, as they appeared to have understood the complexity of her son's situation.

*We thought he was well, very well, better than he had been for over a year but then he had another relapse just two weeks after that. In both relapses, me and his care coordinator with the Early Intervention Team, who is fantastic by the way. She is absolutely marvellous and the doctors are marvellous. [Storyteller 10]*

However, when her son needed to be hospitalised, she described a very different experience. During these times, she identified staff's lack of understanding of Asperger's syndrome as contributing to difficulties in securing appropriate care for him.

*They offered some support to the staff on the ward because code of practice says that if they lack the expertise, that they have to call in and get professional advice. I understand that [unit] did go and offer advice on how to deal with patients with autism and in her words, she said, "Well, some of the staff were receptive but others just thought it*

*was a waste of time." I can understand that. Not everybody wants... if you don't know anything about autism and you've got somebody who is in their 20s but actually their emotional age is about 12 then they can just seem irritating. We're always blamed for bad parenting.*

On at least one occasion she and her son experienced a significant failure of care. She described the staff's lack of understanding and their resulting failure to appreciate his vulnerability as contributing directly to a sexual assault on the wards.

*He's also gay. While he was on the ward he was groomed by another patient who'd been there for about a day and a half. They knew this. They chased [son] out of the other guy's room at one point and then the guy persuaded [son]. [Son] was consensual to start with and then as it went on, he said, "No." Staff intervened because they found them, they could hear them in the wet room. They called the police. The police came and they asked [son] whether it was consensual and he said, "Yes," so the police went away. The police then forgot to write a report about that so the [name of unit] didn't get it until two and a half days later.*

*[...] So between the police and the hospital, they failed to keep him safe. [...] They were negligent and this again comes back to what I was saying about the lack of communication, that the serious incident investigation report from the highly redecorated version that we saw, makes it plain that the other guy was a risk factor, that he had a history of sexual offences. This information was buried too far down the notes so that staff were not aware of it.*

Throughout her story, a lack of resources and a lack of beds, in particular, were identified as causing problems for her son, putting him in a number of unsafe situations. For example, following his assault, he was left to spend more time with the perpetrator as there was nowhere else for that person to go.

*So the first time [son] was sent to [name of hospital and area] was when he was assaulted by this other patient, and I call it an assault even though the hospital call it a relationship. The other patient remained on the same ward for 48 hours afterwards. Son was being told not to speak to him although the guy was trying to engage with him in the corridors and communal areas. I mean it was just quite outrageous. [Son] phoned me at one point saying that one of the nurses had threatened to take his leave away if he spoke to this other guy again. I went and asked that nurse about it and they said no they would never have done that. They might have said he would be timed out to his room. Anyway, so that guy had to stay on the same ward for 48 hours because there was no bed available in the trust for them to move him to.*

On another occasion when her son was very unwell and they went to hospital, there were no beds across the country which meant that he was sent home from A&E rather than being admitted for care.

*When we got to A&E, triage saw us very quickly and then we went to sit in the psychiatric liaison waiting room. [...] Then we saw the psychiatric liaison nurse after about an hour, which was good. She said, "There are no beds available anywhere, nationally, not even in the private sector. Take him*

*home. Get some over the counter Promethazine". It's an antihistamine in fact but it also helps you sleep and is often used for psychiatric patients to help them sleep, "Get some over the counter Promethazine and I'm sure he'll sleep." I said, "Can I talk to the duty psychiatrist?" and was told, "The duty psychiatrist will tell you exactly the same thing, there are no beds available nationally, not even in the private sector." If he'd been brought in under a Section 136, we'd have got to stay but because he came voluntarily, ill as he was, and he was obviously ill.*

After he was sent home from A&E the situation deteriorated significantly. Antihistamines were an inappropriate response to the situation, and as our storyteller had expected, they did not work.

*Anyway, so we went back home, got the Promethazine, it didn't work. He didn't sleep. [...] So he went out about 7:30 in the evening. He kept in touch with me on the phone. Then the last I heard of him before his phone ran out of battery was 11:30 in the evening when he said he was on a train to Watford. So I called the police. I said, "He's not very well and he's in danger of getting himself into situations that could be harmful to him." They couldn't do anything but they took a missing person report. Anyway, he disappeared all night, came back under his own steam at about 7:30 the next morning, very distressed, very agitated, babbling complete nonsense. [...] A guy had invited him into his flat, total stranger, and tried to steal his boots off him, chucked him out. Then he approached a taxi driver who got a baseball bat out of his cab and threatened [son] with it. It's kind of a blessing really that he was quite as manic as he was. I think*

*people wouldn't come too close. [...] So he could have come to quite serious harm during that night. He could have done serious harm because he was so out of it.*

The storyteller described her efforts to get her son appropriate care in a safe environment. The stress she was under is palpable throughout, as was her frustration trying to negotiate with healthcare staff who were, at times, very unhelpful. Her negotiations sometimes revealed conflict within the teams who were supporting her son.

*But the biggest problem I have is that the teams don't talk to each other enough, they don't spend enough time on the individual. Or if they do, they're arguing amongst each other and that I found most dispiriting, to be in a ward-round meeting where the psychiatrist in charge of [son] has almost shouted at the care coordinator who was doing her best to try and get these forms filled in for the replacement and him almost shouting at her, "It's your job, you do it." She couldn't do it because the nursing staff wouldn't do it.*

At other times problems emerged where staff in different services did not talk with each other, or with her. This had a disruptive effect on the care he received.

*See now [we] think we've got it sorted out by trial and error that he has medication of the very strong kind that we can apply either as a family or the care home if ever he looks as though he's on the binge of not sleeping. He goes up so fast, two nights without sleep and that will be it. So we did that. That was a learning lesson that any team would have had to try and I understand that psychiatry is a fine art. You try something, see*

*how it works, try something else, see how it works. If you've already tried something in the hospital, noting take Clonazepam away too fast or any Benzodiazepine for him, take it away too fast and he'll start going up again. It's visible within two days. Now, if the hospital knew that, how come the outpatient team didn't know that when they reduced his Risperidone? How can we get no information about what exactly was being given to him in terms of benzos while he was at [name of hospital]? The liaison isn't sufficient. If they're going to put people out from them into the private sector, they have to have much better liaisons.*

She also described problems that occurred when her son was admitted to a hospital that was out of the local area. When he was placed outside of his 'home' service's catchment area, the local team were no longer inputting into his overall care or being informed of any ongoing treatment. Staff at the out of area hospital refused to talk to her about his care over the phone, which meant that it became difficult for her to understand what was happening to him.

*The care coordinator couldn't go and visit [son] while he was out of area, not allowed to. Her manager won't let her because it's too far away. So while [son] is out of area, the care coordinator doesn't know what's been given to [son]. I don't know what's been given to [son] because if I ring up the place down at [name of the out of area hospital], they say, "We can't give that information out over the telephone. You'll have to come and visit. Talk to the doctor." So I have to take a day off work because the doctor is not there at the weekend. £40 travel as well on a Sunday because you have to have taxis from [name of place] to this place.*

*What would have been better there is more communication. I just think it is a big problem that the teams are not communicating effectively with each other. There are too many team rivalries, that the hospital staff, lots and lots of them are fantastic. There's a few bloody-minded jobsworth but you get them in any profession.*

At times, she experienced behaviour from staff that was discriminatory towards her son. Staff assumed that her son did not have capacity to consent to sharing information with her or other services, rather than assessing his capacity to consent. This storyteller was aware of her son's rights under the Mental Capacity Act (2005), in which the emphasis is on assuming that someone has capacity unless proven otherwise.

*A few days after [son] was assaulted, I went charging in there furious to the ward manager, demanding to know how on earth this could have happened while [son] was detained under section on their ward for his own safety and they couldn't keep him safe. Now, instead of just telling me, "There's an enquiry under way and we'll be able to tell you more, we don't know the full facts yet, we will find out and let you know," I would have gone away. Instead, what he said was, "Oh well, there's not much I can tell you because [son] hasn't given his informed consent to share information with you."*

*So I produced, out of my bag, the informed consent form that I'd already done when I'd previously claimed for some lost property so there was the form. The ward manager said, "Well things are not quite so simple as that because there's also the issue of whether he has capacity to give consent." This is what I'm pursuing as a*

*complaint because there's absolute... I mean that's a cavalier way of using the legislation, legislation that's supposed to protect somebody whose interests might be overridden by unscrupulous or overzealous staff and family.*

*It's supposed to be individual decision based. It's not supposed to be a blanket assumption that this person has no capacity. I don't know the law in detail but I've read enough about it to know that each thing has got to be done as a decision based thing with the proper support and the proper explanations.*

Our storyteller explained that his capacity had not been formally assessed, and she felt that the staff were working on an assumption that he would not have capacity to make decisions (contrary to the Mental Health Act). She felt angry about this because if they assumed he did not have capacity to make decisions, he would be denied the ability to make choices about his own care.

*But to use it in that way, as a cloak, "You're not going to come past this because we're not going to give you information because it's confidential even though this person has said that they're happy to share the information with their mother, nearest relative, no, you still can't. You still can't because he lacks capacity." So they seem to be hovering around this assumption that [son] lacks capacity for anything. I mean where does that leave people who are locked on wards? I'm still outraged by it.*

A number of times, she felt that her own experiences of caring for her son and the expertise she had gained through doing that were ignored or belittled.

*But there is a kind of ethos at the [name of hospital], not on triage, we've now sampled three of the four wards, a kind of ethos on certainly [ward], where [son] was ten months, that carers are an unnecessary intrusion. The involvement of carers I know is part of the triangle of care, it's part of the Trust's policy [...] No, it doesn't happen. It happens with the community team because the community care coordinators are fantastic but they're overworked.*

*So for example, one thing that I suggested to them, because they kept saying, "[Son], don't do this. [Son], don't do that. [Son], if you want to come off one to one, you've got to stop doing blah, blah, blah." I said, "Look, why not give [him] a list of three things or five things that you would like him to do every day. If he succeeds in doing it, give him a reward." "We can't give rewards here."*

*I said, "Well look, he likes poetry, just Google a poem and print it out. That will take 30 seconds and he'll take it away and read it." They did it for about two days. It's alright, I kept doing it. I sent him a text poem every day. But you would have thought just finding something that an individual patient actually likes, showing that you're actually paying attention, that you care, could actually alleviate half an hour's worth of struggle.*

Several times in her narrative she explained that because her son's situation was complicated, a flexible approach that was able to take into account his Asperger's syndrome would have been best for him. In particular, she identified points in her son's treatment in which staff were unwilling to see him as an individual and insisted

on applying strict rules to him which were likely to exacerbate, rather than calm, the situation.

*...if you're on one-to-one [observation] on that particular ward in the [hospital], that particular ward follows [hospital] policy to the letter. If you're on one to one, you're not allowed off the end of the ward, not even down to the garden, not even with an escort. You have an escort stuck to you 3ft away and yet they kept him in there 32 days. [...] No fresh air at all in the hottest time of the year. No fresh air and no exercise. There's a gym in the basement but no. It took four and a half months to get the referral for [son] to go to the gym but you can't go to the gym if you're on one-to-one. You can't go to the garden if you're on one-to-one even though the garden is enclosed now. It's absolutely shocking.*

*I kept saying, "What [son] needs is... look, you've got somebody who is there on one-to-one with him for his protection, not because he's getting violent." Well, maybe he did because fights did break out but, "You've got one person who's assigned to him, why can that one person not take him down to the garden? Why can that person not take him down to the gym?" "Oh no, this is the policy and if you start bending the rules..." This is what the nurses told me.*

*"If you start bending the rules for one patient then you have arguments with every other patient." One size fits all. But what you needed was something in the middle, a part of policy. This is another type of observation.*

Through her narrative it was clear that this storyteller has become knowledgeable about many aspects

of mental healthcare, likely as a consequence of needing to negotiate a complicated system while attempting to secure appropriate, safe care for her son. While talking to us she was able to quote figures and findings from official reports on different aspects. For example, she had this to say about hospital beds:

*Other things that could help? The CCGs and [Trust] build appropriate hospital accommodation for at least 20 people, if not more because if the Crisp Report is correct and 16% of patients who are currently on acute wards are well enough to be discharged but there isn't anywhere for them to go, then that would alleviate the pressure on the beds if there was somewhere for those patients to be discharged to but that's a political one. I mean it's a huge thing.*

*The reason why [service] are spending three times as much... the beds at the [private hospital], the ward had 17 patients on it and each of those patients on just that ward was an NHS patient at more than £500 a night. [...] It's only going to get worse but [Trust] could actually make things a lot better for people in the London area by providing the hospital beds that are needed.*

*So they either have to build a new acute hospital or they have to build the accommodation for that 16% of people who are well enough to be discharged so that they're not at over 100% capacity.*

*We know that it's over 100% sometimes because occasionally you'll find somebody who hasn't been quite discharged, camping out in one of the sitting rooms because there are no beds.*

We felt there was a notable difference in tone to this narrative compared to the others. Elsewhere, there was often a palpable sense of confusion at some points. In contrast, this storyteller spoke with clarity about what should have happened to her son, and a clear sense of anger about what actually happened. She was able to pinpoint where aspects of his care were good and where it was substandard. She was also able to identify parts of the system that do not work well together, which enabled her to locate the source of some of the problems in the care her son received. For example, she had this to say about the impact of stretched resources on her son's care:

*So last May there was no psychiatrist because the only psychiatrist with the [name of hospital] early intervention service, his mother had just died so he was on compassionate leave and they hadn't been able to appoint a locum. They'd advertised the job. So this is another problem. 20% of the nursing posts are not filled, even though they've been advertised. So they're working with staff who are overworked. I mean accidents are going to happen. I think we're quite lucky that [son] didn't come to much more serious harm than he did but already, I think that's harmful enough.*

*From a service point of view, 20% of posts are unfilled, they're already stretched. The staff are doing a quarter of as much [more] work as before so quite understandable that they don't want to spend extra time, spare time, their own time learning about autism. Some of them did. Some of them are fantastic. Some of them, especially the ones with children, understood that anything that you do that gets a five or a six year old or a group of five or six*

*year olds to actually sit and behave, do what you want them to do, any tricks like that.*

Listening to this story, we could not help but feel that this storyteller's experiences – and those of her son – had been traumatic. There was a deep sense of frustration and outrage in her narrative and the impact of these experiences on her family was profound.

**Interviewer:** *How has it affected your family situation?*

**Storyteller:** *Ruined it. But on the one hand, having a kid with ASD, it's already hard work. Lots of relationships don't survive having a child with ASD. The younger one is terribly neglected but he seems to get on with it alright. He's doing pharmacology at UCL. Bad parenting? In his case, yes, lots of neglect but he's just got on with it by himself.*

## ANGER AT THE SYSTEM

### Dolly's perspective

“Hearing this mother's story made me so angry at how services have let her down. Sadly, this is not a one-off. When will the day come when stories like this don't happen, or happen very rarely? I hope in my lifetime, I hope I don't go to my grave with the system still doing that to people.”