



Real life story: Making a complaint without the use of language: A mother's account

My daughter, Rachel is 26 years old and has multiple impairments – cognitive and physical impairments as well as complex health needs. Rachel is a very sociable adult – communicating through gesture, eye-contact, body movements and changes in mood and routine. Her methods of communication are unique to her and in order to interact with her, family, friends and staff need to understand her communication. She does not use language – although she makes ‘sounds’ and she does not understand language, apart from the odd word – such as her name. In order to assist everyone that interacts with Rachel she has a ‘communication passport’ – which explains what her gestures etc mean. Her ‘passport’ has been compiled by her Speech and Language therapist in consultation with all those who know her well – so that we have some agreement on what her communication means and how we should respond to her in a consistent way. She is also engaged socially through intensive interaction – to develop her (and our) skills at non-verbal conversation.

The following is our account of how using Rachel's agreed communication signals and our concerns we made a ‘complaint’ together about her day service. I hope this illustrates how people who do not use language can make complaints – they just need someone to notice what they are telling us (or complaining about) and to act on their behalf within a system which is based on language and cognitive ability.

Our city, like so many areas of the country, is working to ‘modernise’ their day service and this means that disabled people using day services are often moved to venues which are part of their local community. Rachel started her ‘day service’ in a purpose built building – she appeared very happy there – but staff felt that she was ready to move to a service in a community centre, which was local to where we lived and in which most of the other service users were more able than Rachel – both cognitively and physically. They felt that this would provide a more inclusive environment and that the other service users would interact more with her. She was introduced to the service in a planned thought-out manner.

We allowed Rachel time to settle and we then started to have concerns of our own – the environment of the centre was not at all sensory – there was a large table and meeting-room chairs; most of the activities were focused on developing independence skills (road safety; shopping etc) or were based on



table type activities (cutting and colouring); the television in the room was on a shelf high on the wall near the ceiling (we were sure Rachel did not realise it was there even when the group was watching a video). Much of this arrangement was because other groups used the centre and room in the evenings and weekends – so it was a shared facility – and could not be made more sensory or fit for the purpose of a day service. Our other concerns were around a lack of storage space so everything had to be sent in daily; there were no kitchen facilities – so lunch was purchased from a local café; the group regularly went out and on days when Rachel had medical appointments (which are more frequent than other disabled adults) we had to drive around the city to meet the group (which was difficult as we both work).

However, more importantly Rachel started to indicate through her non-verbal communication that she was very unhappy at the centre. Her main communication was boredom – she indicated this by spending most of her day asleep. She had a diary which staff completed each day – and they were reporting daily that she spent half of her day asleep (she does often sleep due to her nocturnal seizures – but this was more frequent and consistent over a long period of time). She was refusing to take part in activities that previously she enjoyed – by turning her head away, not making eye contact and then going to sleep. She was not showing any of the communications which she uses when she is happy – smiling, kicking her legs out, making kissing sounds. When she came home she was indicating that she wanted to go out, be pushed in her chair – she does this by banging her head on the headrest. She was often extremely hungry and thirsty at tea time. Because Rachel was in a local service, she was often seen by friends and neighbours in local shops, restaurants and pubs, and they reported she was either asleep or appeared totally disengaged with the rest of the group.

I made a number of attempts to address the concerns we had and that Rachel was expressing by visiting the day service and talking to the staff and managers. Whilst they attempted to address those issues which they could, this was not making any difference to what Rachel was telling us. The final straw came when we were told the café they used to purchase lunch was closing and would we be prepared to send her lunch in with her. Rachel's range of foods is limited and we are both busy people, so I asked for a review of her service and asked that it be chaired by a senior manager. I prepared all the 'evidence' I had collated from Rachel's diary and other sources and made a 'complaint' via her review meeting.



Although the managers did not respond immediately, they agreed to meet us a few weeks later once they had done their own investigating. The result was that Rachel was moved to a purpose-built centre and the day service at that particular community centre was closed. The managers agreed that the centre was 'not fit for purpose' as a quality day service. All of the service users have been included in other centres and a year on Rachel is consistently showing signs of enjoyment in her new day service.

As someone who is very committed to Rachel being included in her community and using community facilities, it would have been easy to ignore Rachel's non-verbal signals and make excuses for what was happening. However, if we are to ensure that people like Rachel are enabled to make complaints, we need to give priority to our role 'as guardians / protectors of their rights to be heard'. We need to include in all complaints procedures ways of ensuring that there are staff and families who are either able or helped to collect 'the evidence' from disabled people with unique methods of communication so that these types of procedures are inclusive to all disabled people regardless of impairments.

Rachel's mum¹

¹ The names in this story have been changed to preserve anonymity