



Look behind the label

Laura Wardrop says with the right support people with so-called 'challenging' behaviour can live an independent life in the community

My organisation, Partners for Inclusion, is known for supporting people with 'big reputations', people who are labelled as 'challenging' or 'difficult to support in the community' or 'could not have their own house'.

But we always try to look behind the label. It is our belief that everyone can live in their own house, in a street, in a community. The only challenge is getting the support right and sticking with the person until a way forward is found.

For providers, the first step towards achieving this is the set up of the organisation itself. We support just 45 people at any one time and we will not support more. Continuity is fundamental. It's important to value and work with the people you already support, not always have your energy focused on new people.

Each individual should have their own unique, individually tailored service, born

out of bespoke planning. Some of the people we support stay at home with their parents, others have their own home. For the latter group, each person has their own tenancy or mortgage. Tenure is not linked to support.

Each person has their own support team, made up of staff matched to their own staff 'blueprint' – a detailed record of what makes the right member of staff for that person (and indeed what doesn't.)

The key is:

- keeping it small
- individually designed services
- people having their own tenancy or mortgage
- individual teams, with carefully matched workers.

The money we are paid for each person we support is viewed as the individual's and not the organisation's. This allows each service to spend it's money in the way that

makes sense locally and keeps the money as close to the person as possible.

So how does all this relate to making a difference for individuals, particularly those with so-called 'big reputations'? To answer this we need to consider what doesn't work.

We know that, in the not too distant past, society considered people with learning disabilities should be neither seen nor heard. They should live in big institutions, out in the country and left to get on with it in big wards, lumped together according to diagnosis or behaviour. Thankfully, we are now more enlightened, but have we really learned from our previous mistakes?

Many people with learning disabilities continue to live in group homes or settings that are not their choice and don't make sense for them. This seems to be particularly the case for those most vulnerable people with the label of 'challenging'.

Often those who do challenge are those



Good person-centred planning

An example of what it should not say is:

- When Joe gets upset he should be encouraged to return home.

An example of what it might say is:

- Sometimes when Joe is out he may become anxious. He lets us know this by shaking his head and counting on his fingers. If Joe does this staff should say to Joe "OK Joe, I can see you're not happy, let's walk back to the car and go home". This lets Joe know you understand how he's feeling.

Staff should go on and prompt Joe to gather his belongings by saying: "OK Joe, get your things". When Joe has got his things, staff should walk alongside him to return to the car. Joe should always walk on the inside.

On reaching the car, staff should open the passenger door and say to Joe: "OK Joe, you get in the car now" and let Joe get in the car. Joe will step into the car himself and normally put his seat belt on (detail of how Joe travels in his car will be set out in another section). If Joe does not put his seat belt on, staff should prompt him by saying: "OK Joe, can you put your seat belt on?" Our experience is Joe will always do this. In the event Joe will not put his seat belt on, staff should say: "OK Joe, I'm going to wait outside the car until you are ready to put your belt on and then we'll go." Staff should then close the car door and wait close by on the pavement.

The best and possibly only predictor for the future is the past, so:

- learn from the past
 - capture the detail
 - write it down
 - and keep on learning.
- Debrief what works and what doesn't (and write it down!).

Obviously good person-centred planning is not static. It evolves with the person, but changes are not random, they are made in a planned, thoughtful manner, following detailed debriefs. It is only by doing the detailed work around past incidents that makes it possible to come up with a response that is most likely to work.

A bright future for Sean

Sean* is 44 and has a learning disability. He also has labels of autism, bipolar disorder and sexually aggressive behaviour. His history stated he has made repeated physical and sexual attacks against women.

Sean does not use words to communicate. He lived in a large institution from the age of four until he was 38. He moved from hospital into a small group home with two other people with learning disabilities. During the first year Sean became angry many times, sometimes hitting out at his housemates and staff. Nothing changed for Sean as a result of this and he just kept getting more upset and behaving more aggressively. One night he became so upset he was detained under Mental Health Legislation. Sean then lived in a specialist unit for years and continued to be upset.

But now Sean has his own home where he has lived for more than three years. He has a dedicated staff team and he is doing well. He has not had an easy time and working out how to get the 'fit' right for him has been tough at times. But perseverance has paid off.

Sean still has times when he is upset and angry, but they happen less often and every time we debrief and learn from it. Sean has now been on several holidays, is well known for all the right reasons in his local community and is out and about every day. His future now looks bright.

*not his real name.

who have been most damaged by their previous experiences and yet they go on to have the least choice in their future. People with 'reputations' seem to be viewed as more suited to specialist units or homes, and end up in settings with limited staff and resources, living alongside other people who show their feelings in the same way. Yet the reaction is one of surprise when the person continues to challenge.

What is needed to support someone who challenges is a service that fits them and the tenacity to keep looking for that fit through the tough times. It is important to put together a tailor-made plan, initially garnered from all the people who know the individual well, drawing on all the learning from the past and agreeing on how it will work in the new service. It should be tight and specific, and all those involved in the person's support must be signed up and in agreement. ■

