Listening to People Using Services

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(2922 words excluding references)

Behaviour carries meaning, no matter how disruptive or dangerous, and it might be considered as complaining, telling us something isn't working for the person. This chapter suggests listening to the voices and stories of people using services, interpreting their behaviours as communication, is helpful for crafting good support.

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Challenging Behaviour As Symptom

Challenging behaviour may be thought of as communicating messages concerning the quality of life, the health and happiness of the person. Think of such behaviour as 'exotic communication': whilst unconventional, it is effective, because people respond to seeing or being someone harmed (Ephraim, 1998). We can ignore a request, seldom a bite.

> *Family members and personal assistants have supported Amal at home for many years. Following an increase in challenging behaviour, the twenty-five year old arrives at a new service. Amal has limited verbal communication but is clearly distressed. The service is far from home and the people she knows and far from ideal, but it is the only service willing to offer Amal temporary respite. Amal arrives with her clothes, support plans written by personal assistants & family, and copies of assessments completed by her Social Worker.*
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> *The service team work hard to make sense of the information, but the manager feels the documents are vague and contradictory: she gets no sense of Amal as a person. Two workers are allocated to create support strategies based on what they learn from spending time with Amal: what works, and what doesn't, in making Amal happy. The most urgent need is to understand Amal's screaming and hand biting. The team try different approaches & new activities in order to gauge Amal's responses.*

Challenging behaviour is a symptom of an unquiet and unhappy life. Challenging behaviour keeps happening because it gains or avoids things better than anything else the person currently knows. This does not imply the person intends to convey anything, but any behaviour becomes meaningful if we think it is telling us something and respond accordingly. Often challenging behaviour is viewed as a problem to solve

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not a message to be understood (Pitonyak, 2005). Challenging behaviour is telling us the person has few other ways in which to exert choice and control.

Person-Centred Support

To understand challenging behaviour fully is to appreciate not merely antecedents and consequences but the *contexts* that influence a person. Contexts include the preferences of people, their history, their goals, their ability to make choices that are respected, and their communication and social preferences. These contexts describe their story: who they are and where they come from. To be person-centred is to understand conflicts between the person's story and the support they receive, and to work in a manner that reduce such contradictions.

Some people communicate in ways that are difficult to interpret. We are then required to invest time and imagination to try out things we suspect the person will welcome. Such things must enhance the dignity of the person and improve their quality of life. The person's responses to our best efforts will tell us whether we're on the right course or need to change tack. Slowly, we grow an understanding of what the person prefers. By paying careful attention to their reactions we can create support strategies. We soon develop a significant list of items that the person responds well to, including

- Places and spaces the person enjoys
- People, communications and the type of interactions the person welcomes
- Favourite activities, items and routines to which the person responds positively.

The team employ ABC records (antecedents, behaviours & consequences) to understand challenging behaviour: when and where it occurs, what is happening at the time, what predicts it and what follows. This helps them evidence what they believe Amal's behaviour is communicating. After two weeks they find regular patterns. They learn:

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1. Following a disturbed night, when woken for the morning routine by staff who are quite directive, Amal is likely to scream; Amal stops screaming once people leave her in peace. Amal doesn't scream if she has slept well, if staff are less directive, have more time to gently wake Amal with a drink, and sing with her.

2. Amal bites her hand when she has had no support for fifteen-minutes or sees others talking or enjoying activities. Before hand-biting, Amal may scream. Hand-biting usually only happens after lunch and before dinner. Hand-biting gains attention, and often, activities.

Screaming in the morning means, "I'm tired and don't like how I'm being supported". Screaming in the afternoon means, "I'd welcome some attention". Hand-biting means, "Give me attention! I'm lonely or bored".

Challenging behaviour exists in the space between the person and those who support them. To understand and address challenging behaviour we have to get to know the person in order to provide the kind of support they need for us to deliver both a good quality of life and increased choice and learning.

Supporting individuals in a person-centred way is not for the faint hearted, the under-supported, or the indifferent. Person centred support is provided by knowledgeable and passionate people. It takes commitment to work in the tensions between the demands of the team and the demands of doing what is right by the person.

Taking Amal's behaviour as communication means the team craft two key documents to help them support her in a more person-centred manner. An interaction profile sets out how the team promise to support Amal with her morning routine, as well as how to engage her in regular low-demand

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and fun activities. The team knows Amal prefers some staff to others, and the profile describes how to develop rapport with Amal. The document sets out the need to respond to screaming rather than wait for the more serious hand-biting. Crucially, this also describes a strategy to ensure Amal sleeps well: this involves 'quiet' time from 9pm, a warm bath, subdued instrumental music, and a hand massage. Amal enjoys a snack before bed. A V-shaped pillow helps her settle comfortably, as does a golden night-light. If Amal is relaxed, she sleeps better, and sleeping better means Amal is less tired come morning, more able to listen to staff, and less anxious.

The second document is a communication passport. This described what methods of communication work best for Amal. Less talk and more signing seem to result in fewer problems but Amal also responds well to symbols, and she will point to symbols for certain foods and people. The team now use symbols & signs as their primary form of communication. The team ask a local Speech Therapist and Psychologist to work with them to verify their discoveries and to offer them further advice.

Person-centred support is an upstream solution: providing the kind of support that meets the expectations and needs of individuals may contribute to amending or avoiding situations that lead to challenging behaviour. As such, person-centred support can act as an antecedent intervention.

For Amal, the team change how they ask her to be involved in activities, they focus on preferred activities, they embed less preferred activities in fun interactions, and they teach alternatives to screaming and hand biting that achieve the same outcomes. These changes help reduce challenging behaviour.

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Person Centred Planning

Person-centred planning is the foundation upon which a meaningful life can be crafted and tailored services delivered (Freeman, *et al,* 2015). Using such approaches clearly demonstrates service organisations are committed to taking people seriously. Being person-centred is not optional: it is the job. It involves regular ongoing meetings to discover and describe what support the person requires to achieve what they want to achieve. Often services are built on our ideas of what suits people without bothering to tailor such places to individuals.

If it is true that regardless of our good intentions "we cannot represent others in any other terms than our own" (Van Maanen, 1988, p.12), perhaps it is useful to gather the insights of others about what might serve the person best. Person-centred planning is a collaboration: people work in partnership to describe what they know. Families and friends are experts through experience and their insights about what people need to be supported well don't necessarily rely on busy professionals. They can provide unique perspectives and stories. There are two outcomes of planning: better understanding and better support. The plan is not the outcome, but the springboard to deliver what the person needs. A plan is never finished: it grows as knowledge is gathered from supporting the person.

> *The team know that supporting Amal well is only one element of good service: they need to establish what kind of future Amal might prefer. Having goals and things to look forward to is important for many, and given the sudden changes in Amal's life some certainty is felt to be vital for her well-being. The service organisation employ two people with good experience of person-centred planning. The aim of their work is to describe a desirable future for Amal. This will help Amal's Social Worker and family think about what happens next.*

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The team arrange a series of meetings between family members, Amal's Social Worker, and one of her ex-personal assistants. With Amal present, they describe what good support looks like for Amal, and they sketch out desirable futures. Amal contributes by signing, smiling, and selecting symbols but also through others having learned what matters to her. For Amal, any future involves being close to home, to the places & people she knows. Amal's team contribute their perspectives: Amal enjoys being busy, going to new places whilst enjoying familiar locations, trying new activities and meeting new people. Food is important to Amal (she loves to cook) as is predictability and people keeping their promises. Any future arrangement should encompass these attributes.

Plans can include descriptions of

- The methods of communication the individual uses
- The living arrangements preferred by the person
- How the person prefers to be supported
- The activities and community spaces the person enjoys
- Goals and hopes for the future.

A number of different planning methods exist and the one we use depends on whether we are seeking to understand how better to support someone now, or whether we wish to discover a desirable future. Most plans use more graphics and fewer words and they often describe how to support people to get to where they want to be, and how they wish to live (Sanderson *et al,* 1997).

Delivering a good quality of life is not simply an aspiration or outcome, but an intervention in itself. Tomorrow never comes for too many people whose behaviour challenges others, and many are expected to wait for their behaviour to ameliorate prior to receiving the opportunities that is their right. Quality of life seldom spontaneously occurs, and people with IDD usually rely on the work of others to

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enable daily things others take for granted. Support needs to be well-organised and well–led in order for it to be person-centred.

Choice

A good quality of life is a subjective experience. Individuals value different things. But quality of life might be said to be the experience of a rewarding, enjoyable life surrounded by a rich network people we like. Did the support you provided people this morning or this afternoon deliver the same?

Most experts agree that self-determination (control & choice, making decisions, preferences expressed and respected by others) is an important part of a good quality of life (Schalock & Verdugo, 2002). There is evidence showing that offering choices to people lessens challenging behaviour (Carter, 2001), making it "irrelevant, inefficient, and ineffective" (Carr, *et al.,* 2002, p.5).

> *Amal now has her first person-centred plan. The respite service is using elements of the plan – along with the interaction profile and communication passport – to inform their support of Amal; it tells them how to work and what to measure to show success. They now record not only the rate and duration of challenging behaviour, but also the rate and duration of happiness & enjoyment. One of the important predictors of challenging behaviour is Amal not having her choices respected: the team measure the number and type of choices Amal is offered and makes, to capture information about what she prefers.*

Having choice is important for people. Choices can be small yet significant for happiness (for example, the sort of food we want, the activities we enjoy), or choices can be large (for example, where we live, with whom, how we are supported). In the UK the law assumes capacity exists to make choices and that what matters is not making the *right* choice but *their* choice. Some decisions are more demanding that

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others, however choices become more informed the greater our experiences of the options and outcomes.

Happiness

Amal's story consists not only of descriptions about how to support her, or respect her wishes, or enable her to be active; her story includes knowing the things she values, the people she loves, the difficulties she faces as a human being, and what she needs to be happy. Amal's story is happy and heartbreaking but not uncommon. Services and professionals often collect paperwork not stories, and so only catch a glimpse of the people they serve.

> *Amal is well supported by a team of people who enjoy being with her. There's evidence of good rapport, communication is consistent, and Amal is enjoying her life: challenging behaviour has significantly reduced by improving the quality of life experienced by Amal. The weeks turn into months, then a year: it takes time for Amal to develop positive relationships and trust. Amal's family are happy, too: they want Amal to live in her own place.*
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> *After thirteen months, the team is saddened when told Amal will be leaving in a matter of weeks. Her Social Worker has found a service near her family. The respite team are fearful the new service doesn't make mention of Amal's person-centred plan. But they have collected a huge amount of information and knowledge concerning how best to support Amal and how to listen to her: they have accrued an understanding of her story. The team will pass this on, hoping someday others will pay attention and listen to Amal.*

When inducting new staff, positive stories should balance war stories. Many individuals have plans written about them that ensure staff keep them safe during

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incidents of challenging behaviour. Far fewer have plans that describe how to ensure happiness is maintained, choice is not withdrawn and ruptured relationships are mended. Services keep antecedent-behaviour-consequence (ABC) records for challenging behaviour, when they might also keep ABC records for appropriate or happiness. Happiness is a goal people can relate to and should be an accomplishment of support (Carr, 2007).

The above methods – person-centred planning, person-centred support – can contribute to the inclusion of the voices of people using services. Such approaches can shape our understanding of what the person needs to avoid or amend predictors of challenging behaviour, and they can give us insights into bigger issues facing them.

People may live in a place and still not belong. Belonging comes from being active in a place, being valued in a place, and enjoying time there. Happiness and belonging are as valid as any other factor contributing to quality of life, and yet they are often seen as of secondary importance in 'managing' challenging behaviour. It might be that working to deliver happiness and belonging contributes to reducing challenging behaviour.

Implications

At the heart of our work to understand and respond constructively to challenging behaviour is the requirement to work in a manner that delivers person-centred interventions. Including those too often excluded, who have learned the only way others listen is to hurt themselves or others, takes time and imagination. In the past services operated as if the people using them were passive recipients rather than active partners. People with intellectual disabilities are people to be understood, not puzzles to be solved; they are not square pegs to be forced into round holes others have carved.

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Some people can tell us very clearly what they like and what they don't. Some people take a while to trust us. Some people show us what they like through their reactions to our work. Some people inform us through their challenging behaviour. All these are hard to hear when we don't believe the person can tell us anything of value. Our attitude can act as a barrier to hearing what people are communicating.

Challenging behaviour speaks of important things but the absence of a thing can tell us as much as its presence: when challenging behaviour reduces the message seems to be, *I'm living the life I like.*

Key learning:

- How we think about people influences how we work with them.
- Thinking of challenging behaviour as a form of communication means we spend time trying to understand the message.
- Person-centred planning refers to a number of methods of gathering information about whom the person is, how they prefer to be supported, and their future aspirations; a plan describes how to support people better.
- Person-centred planning should involve as wide a range of people as possible, including the person, their friends and family, and people who know the person well.
- We can include people in decisions by asking them, by considering their responses to our support, and paying attention to their choices.

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