Editorial

Rachel Perkins and Julie Repper

The next big thing will be a lot of small things

In April, we were invited to speak at a conference at the University of Tilburg in Holland entitled "The next big thing will be a lot of small things" (to be exact, Julie was invited to speak and could not do it, so I was asked in her place!). We had been asked to talk, as mental health professionals, about our own lived experience of being on the receiving end of mental health services. The title of the conference resonated with our own experience of using services and really got us thinking about the challenges facing our mental health services.

Too often, when we think about improving services we think about the big things. Anyone who has worked in the health and social care arena will have experienced many reorganisations, the merging, establishing and demise of services and changes in structure, accountability and responsibility. In developing services that better support people in rebuilding meaningful, valued and satisfying lives "ten key organisational challenges" have been developed by the Implementing Recovery through Organisational Change[1] programme (Sainsbury Centre for Mental Health, 2009). These have spawned numerous, positive, service developments including the establishment of dozens of Recovery Colleges, the employment of hundreds of peer support workers and changing approaches to risk. Yet the first of these ten key challenges "Changing the nature of day-to-day interactions and the quality of experience" (Sainsbury Centre for Mental Health, 2009, p. 2), while probably the most important, remains the most elusive. This challenge involves thinking not about structures and services but about all the relationships within those services, and thinking about every little thing we do.

It is often the little things that are so demeaning and demoralising. A few words, a gesture, a seemingly insignificant practice can really pick you up or slap you down.

Like trying to get through those locked doors and key pad systems to get to an outpatient appointment – and when you finally get through the receptionist (if they have not been cut in the last round of "cost improvements") – is protected from you by a very high partition and/or glass screen lest you take it into your head to leap over and attack them. Talk about reinforcing images of dangerousness and unpredictability! We know there are concerns about safety, but let us face it, everyone going for an outpatient appointment has been into local shops and a range of other community facilities and they do not have such barricades for protection – even Job Centre Plus have dispensed with them in an effort to appear more welcoming.

Like mental health workers minimising your distress ("look on the positive side, it's not really that bad"). This either makes you feel particularly useless on account of your inability to cope with a not bad situation or it makes you rehearse how bad things really are to try to persuade your disbelieving interlocutor of the grim realities of your situation. Or worse, completely ignoring your distress. One of us well remembers sitting there crying on a ward and staff simply walking past – in fact the only person who stopped and sat down was a student nurse (clearly he had not been fully trained yet!). This does little to inspire confidence and serves to make you feel alienated from those very services that are supposed to be able to help you.

Like separate toilets (and crockery, cutlery, etc.) for staff and patients. What messages does it convey to those of us already feeling inadequate and ashamed because of our mental health problems to find that we are not fit to use the same toilets? Frankly, if the toilets are not fit for staff to use then how can we be fulfilling our duty of care to expect people using the service to use them? Can we really talk about treating people with dignity and respect when such separate facilities for "them" and "us" prevail?

Then there are all the little, rigid, "one size fits all" rules ("no visitors in your room", "you cannot have your mobile phone or your knitting on the ward", etc.). Sometimes such rules reflect a "lowest common denominator" approach to safety: if one person is "not safe in the kitchen" then no one can use the kitchen unsupervised. Alternatively, they may be imposed through ideas about "fairness": it is not "fair" for Fred to have to get up at 8 a.m. if Jimmy lies in bed until 11 a.m. Ironically, the only area in which such ideas of supposed fairness do NOT apply is in relation to medication: "it is not fair for Fred to have clozapine if Jimmy only gets risperidone"! Whether through ideas about safety or fairness, such rigid rules that mean everyone is treated the same ensure that services can never be tailored around individual needs and preferences.

More importantly, staff having discussions about you when you are not present and having notes written about you and not being told what is being said (it has been said that you can always spot a psychiatric patient because they can read upside down!) In theory, the NHS adheres to the principle of "no decision about me without me" (Department of Health, 2012) – yet we know of nowhere in mental health services where this policy is fully observed apart from the very small fledgling open dialogue teams that are emerging.

And then there is the language that is used …

Language matters. Language and thought are intimately interlinked. The language we use to speak and write about people significantly influences the way in which we value them. Although many services aspire to engaging in "strengths-based" care planning, the reality rarely meets these good intentions. A brief perusal of the notes of anyone using services soon reveals that the number of words describing deficits, dysfunctions and problems, far out-weighs the space devoted to strengths, possibilities and personal aspirations. Too often this situation is reflected in the pages of academic journals where most research similarly focusses on what is wrong rather than what is strong, thus fuelling a culture of low expectations:

> […] even the briefest perusal of the current literature on schizophrenia will immediately reveal […] that this collection of problems is viewed by practitioners almost exclusively in terms of dysfunction and disorder. A positive or charitable phrase or sentence rarely meets the eye […] deficit-obsessed research can only produce theories and attitudes that are disrespectful of clients and are also likely to induce behaviour in clinicians such that service users are not listened to properly, […] treated as inadequate and […] not expected to become independent or competent individuals […] (Chadwick, 1997, pp. xii-xiii).

Services are replete with demeaning and devaluing short-hand language like "attention-seeking", "non-compliant", "lacking in motivation" "manipulative", etc. It is interesting to note that some of these "qualities" may be differently valued depending on your position within mental health services. If a clinician persuades someone using services to do what they (the clinician) thinks best, they may be described as a "good clinician". If, on the other hand, someone using services tries to persuade the clinician to do something that they, the patient, thinks is best, they risk being deemed "manipulative". How different would services be if this type of "what's wrong" shorthand was replaced with "what's wrong" language. For example:

■ "attention- seeking might become he/she knows they need help and values our help";

■ "non-compliant" might become "knows his/her own mind and disagrees with the professional view of things"; and

■ "lacking motivation" might become "we haven't yet found out what he/she values – what drives him/her".

"What's strong" language may take a few more words, but the additional effort involved can pay dividends in enabling us to see the strengths on which the person can build. People rebuild their lives not on the foundation of deficits and dysfunctions but on the basis of strengths and assets.

However, what often gets to you most is not being believed. One of the consequences of mental health challenges is that your viewpoint is too often seen as a consequence of your mental health problems: you are seen as an "unreliable witness" of what has happened and basically you cannot be trusted! Often, we find in records phrases like "she says she was a secretary, a student, went to the GP for help […]". While this may be technically accurate, in common

parlance the phrase "she says […]" implies that your interlocutor does not really believe you. Too often efforts are made to check out whether the person "really" was a secretary, a student or went to the GP. One of us well remembers an interaction when she was in hospital. She had been to the gym and afterwards came back onto the ward with the gym instructor. A member of the ward staff asked her "where have you been?" to which she responded, "to the gym". The staff member then turned to the gym instructor and asked, "did she?". Such seemingly insignificant interactions can have a devastating impact on the way you see yourself and services. How different would it be if instead of "did she" the staff member had responded "that"s great – what did you do there?

Then there is the everyday "you" language that assumes that the mental health worker is correct – "you are being aggressive", "you are a danger to yourself" (it is a "fact") – rather than the "I" language that accepts that there may be different ways of seeing things: "I am worried about you". "Your language sets up an immediate battle about who is right and who is wrong: 'You have schizophrenia", "No I don't", "Yes you do" […]. "I language, on the other hand, opens up the possibility of discussion and understanding each other's point of view".

There is an increasing emphasis on "choice" in services – choice of treatment, choice of appointment time, choice of clinician, choice of service (see e.g. NHS England, 2014) […]. Although many using services describe there being relatively little choice around such practicalities, there is probably a more profound choice that is almost invariably lacking: the right to define reality. The right to choose how you understand where you are and what has happened within a framework of your choosing.

In mental health services, it is professionals who define what is wrong with you, why it has gone wrong, and what you should do to put it right. If you disagree with these professional opinions, such differences are not usually understood as a different point of view, but as you "lacking insight". To have insight requires that you recognise that you have a mental illness, recognise the need for treatment, and interpret unusual mental events as pathological (see e.g. Quee *et al.*, 2011). If you lack "insight" you fail to understand the "objective reality" of your situation. Much professional time has been spent by mental health professionals trying to persuade patients to accept that their professional explanation is the correct one […] and at the bottom line professionals can impose their reality by compulsorily detaining people and treating them against their will. But what is the "objective reality" of the situation? With the advent of multi-disciplinary teams, it is becoming less and less easy to have "insight: it is not uncommon for psychologists, social workers, psychiatrists and other mental health professionals to understand the 'objective reality" of someone's situation in different ways. To "have insight" with one professional is to "lack insight" with another!

There are many, many different theories about the nature and origin of mental health challenges, including that there is no such thing as "mental illness". There is no one "true" explanation, the issue is one of power: who has the right to define reality and impose their theory on others. Each person – whether they be a provider or a recipient of services, has to find a theory that makes sense to them and allows them a way forward. How different would it be if, instead of trying to sell their theory, professionals helped people to understand some of the myriad possible explanations and work out one that suits them? Maybe then we could avoid some of the destructive battles that so often occur in mental health services.

To impose your reality on another who does not share that model for understanding can only alienate them from the professionals and services whose help they may need. We well remember working with a young man who had been compulsorily detained for many years. He asserted, despite continued attempts to persuade him otherwise, that he did not have schizophrenia. When, finally, someone explored what he did think had led him to his current situation he said that he had "a breakdown caused by drugs". How different might the course of events that led to prolonged detention have been if his understanding had been explored and recognised as valid in the first place? If we had said "I think you might have schizophrenia" (rather than "you have schizophrenia") thus enabling us to discuss different possible interpretations.

There is much talk about treating people who use services with dignity and respect. This must mean respecting different points of view and perspectives on the world. But it must also mean

looking at the little things – the things we say, the things we write, the innocuous practices that can so demean and devalue. This is not easy. Services are busy places and people using services are often very distressed and may behave in ways that we do not find acceptable – it is difficult to treat with respect someone who abused or hit you. Yet this is the task. To understand and empathise with the anger, the frustration, the distress that led to the behaviour that challenged us. To understand how the world looks from the perspective of the person we are working with.

The real challenge is always to recognise our shared humanity – however different from ourselves the person and their experience might be – and to demonstrate that shared humanity in every little thing we do. It is those little things that will make a big difference.

Note

1. https://imroc.org/

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