

2 Learning from Humerah

‘When people see me they think “physical disability”, but actually it’s my mental health’

Humerah uses a wheelchair. However, her main contact is with the mental health services. Her first psychiatric admission was 19 years ago and her first social worker contact a year later when she was sectioned for the first time. Over the past 18 years she has been ‘a revolving door’, coming in and out of the system periodically. She has been with her current mental health team for eight years. This is multi-professional and includes a psychiatrist and a care coordinator. She has had a variety of social workers and community psychiatric nurses (‘I’ve lost count how many’) and, until she was allocated her current social worker, most of the experience had been very negative.

‘The mental health services find it difficult to have someone who has insight and is articulate and yet on another level is a complete mess,’ says Humerah. ‘It doesn’t make any sense to them.’ It doesn’t make sense because when the professionals think ‘mental distress’ they see people climbing walls, not getting dressed, not able to pay bills. Humerah does not conform to this stereotype. She presents as someone who on one level manages very well, and is described as ‘high functioning’, yet privately struggles with hearing voices, self-harm and ideas of suicide.

Humerah works in a responsible job. She has lost jobs a couple of times on account of her mental health problems. On one occasion she was admitted to an acute psychiatric ward just a week after an appointment to a new senior position. She spent the first three months going to work from the ward but no one at work knew. She works in the social care field and muses that it is interesting how we don’t look down on doctors and nurses when they get ill, yet in social care it seems hard to accept as colleagues people who use services, particularly in senior positions. Workers have clear images of people who use services and though we welcome user involvement, it is a different story if service users also have an identity as professionals and peers. Humerah’s team had enormous difficulties in accepting and coping with her mental health problems. Her treatment by her agency at the time was so fraught that she started proceedings for judicial review of her case.

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Humerah notes that she became extremely litigious, making frequent written complaints and taking legal action in response to her anger and frustration at the poor service she was receiving. Then two years ago her social worker changed. 'My social work relationship has changed beyond belief,' she muses, then smiles. 'I'm no longer making complaint letters or taking legal action.'

What is the difference? What does her current social worker do which has had such a dramatic impact and which has changed the pattern of 18 years?

Humerah describes the difference as 'I feel she is working with me and wants to find solutions that will work for me'. When asked what this means in practice, she says that her social worker knows when to take the lead and when to back off.

'When I'm having a real wobble I stop my medication. I'm quite a danger to myself, and though I can still somehow go into work the rest of my life is a complete mess and I can't take action to deal with it. Logic goes out of the window.' At these times Humerah's worker will do basic plans which include what to do to stay safe, like giving Humerah a timetable. Humerah knows that, as she appears so competent, it is difficult to understand that there are times when she needs this kind of basic care and control. Her worker will say, 'Humerah, is it time to go into hospital?' or she will say, 'We're going to do this or that, I'm not asking you, I'm telling you.'

Humerah observes that it sounds a real contradiction in terms, that having her worker take this degree of control is, at these times, the right thing for her to do, even an empowering thing. 'They just need to take control – and that's not to give up control forever.' She explains that, though she hates to say it, one of the things that works very well for her is when control is temporarily taken away from her. She regards detention under the Mental Health Act as a necessary evil, indeed, she has been detained over a dozen times. 'It takes control away from me, sets clear boundaries.' Humerah recognises that it is not necessarily going to work for everyone, but it works for her. 'It's saved my life several times.' She knows that logically you would not stop taking medication when you knew what the consequences were, but stopping her medication is the first thing that she does when she is approaching a wobble.

Her social worker knows her triggers, the vulnerable points which are likely to precipitate an episode. Moreover, she does not try to reform her or divert her, but just accepts without making a value judgement. Sometimes the worker acknowledges that 'we've reached a point where we're both stuck'.

I wonder whether Humerah knew early on that things were going to be different with this social worker. She is not certain about this (it is two years since they have been working together), but does remember that

the relationship developed very quickly. However, she does remember one aspect of the first session very well. She did say to her social worker that she knew that she was seen as 'a very difficult client', and that before the two of them started running into problems they needed to think about how they could change it. Humerah muses that perhaps this overture should have come from the social worker, to say something like 'I know it hasn't been easy, but ...'. Even so, Humerah appreciated that the social worker did say that she did not mind Humerah getting angry. 'She said she didn't mind me getting angry at her, but she did want me to speak to her first before I went off writing to her manager. That was really good ... It came over to me as, if you've got a complaint and you're not happy with me you need to tell me, and we need to talk about it.' Humerah knew that she could still complain if she wanted to, but that she should first let the worker know if she was not happy with things. This was only fair to the worker.

It seems that communication had completely broken down in Humerah's relationships with previous social workers. She would regularly write letters to the team manager and the head of adult mental health services because she saw no point in talking to the social worker. 'They couldn't see what my issues were and why I might be having difficulties.'

Humerah has severe and enduring mental health problems. She thinks professionals have a real problem because she is not seen as 'deserving'. Ironically, as an articulate person in regular employment she feels that she is seen as not needy enough or deserving. 'I fell outside the needy person category because I don't fit the stereotype of a service user, especially as I work.'

Humerah volunteers that her social worker has told her that she thinks that her journey is going to get worse before it gets better and that it is going to take time. Messengers with this kind of news are not usually popular. No one likes thinking things will get harder, but Humerah says that this social worker helped her understand that unless certain issues were tackled through a mix of therapy and medication, she would not be able to move forward. This came after Humerah had wondered in some distress how come life was actually getting harder, after all these years of mental health services. 'Surely I should be getting better at dealing with it?' The breakthrough for Humerah came when her social worker offered her a metaphor which transformed the way she saw her situation. The social worker said she thought that all Humerah's childhood and adult life she pushed things to the back of the cupboard, just getting on and giving the impression of coping. The cupboard got so crammed she could no longer keep the cupboard doors shut and it all started spilling out. 'When she said that it just clicked.'

I ask Humerah when this happened, how far into the work with the social worker. She cannot remember for sure but surmises that it was

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probably about three months after the change to this new worker, around Christmas-time, which is a bad time for her.

The social worker is now a team manager, but she has carried on working with Humerah. When I ask Humerah if she and the worker ever disagree about things she puts me in no doubt that they do. For example, there is a really big bone of contention about contact by email. Humerah works in a large open-plan office where privacy is hard to find, so she does not see the phone as an option. 'My worker absolutely refuses to let me have her work email address, and she says that if she lets me have it then she has to let other service users have it.' Humerah says that she knows that they don't have many people in work so there would not be much call on the email and that perhaps it would be useful for others, too. Humerah paced herself and decided to bring the subject up again a couple of months later and when the response was still negative 'we had a humdinger'. She thinks that the funny thing is that it works both ways and her worker sometimes finds it hard to contact her, whereas an email would reach her easily! Also, recently, the worker gave Humerah her mobile number 'but I have never used it'. She acknowledges that she and her worker have different views about which is the more private boundary. They agree to disagree.

Another point of disagreement arose around Humerah's CPA (she explains that this stands for Care Programme Approach). She had disclosed something private to her worker, not expecting that she would make it 'public'. Humerah understands that some information needs to be shared with other workers, but if the worker had explained that she was going to mention this information, Humerah would have had the choice as to whether the friend who accompanied her at CPA meetings should be privy to it or leave the room, since the friend was not aware of this information. 'Afterwards I was really angry with her. My worker said although this isn't a family relationship, it is like family relationship, and you get angry and you fall out, but that's OK, that's fine. I could have kicked her for saying that, but actually I thought, yes that's probably right.'

The question of balance is very important, especially around this issue of control. For example, Humerah could remember a while ago she said to her social worker that she thought her care budget should be cut because she wasn't using support workers as much as she used to. What happened was that the social worker said OK, but actually she didn't report back to the head of adult mental health services and she kept Humerah's budget at exactly the same cost 'because she knew that it wouldn't be too long before it would need to be upped again'. It was a lot harder to increase a budget than to keep it steady, and she had known that Humerah would need the increased budget at some point. Humerah appreciated that it was the worker's job to know what was and was not possible with her agency and did not mind that she

had taken the decision into her own hands. 'It comes down to her taking the lead when I need her to.' The important thing, too, is that they can talk about it afterwards.

Humerah has talked about the times it has been important for the worker to take control, but what about the other side of the balance. Did she have an example of the worker letting go? Humerah says that recently she was offered supported housing and she had a lot of discussion with her worker about the pros and cons. She had eventually decided not to move and this was entirely her own decision, with her social worker not offering an opinion but just helping her to come to her own decision.

Another example is Humerah's decision not to have any 'advance directives'. Humerah explains that these are written instructions which people can make when they are feeling well to cover what they would like to happen 'when I go into a wobble'. These would certainly make life easier, but Humerah has made it clear that she would not care what she had agreed when she is well; if she was on a wobble it would become meaningless. 'The social worker has accepted that advance directives are not for me, she's said "fine".'

Humerah's social worker is Asian. Before any assumptions can be drawn she declares emphatically that she does not believe in 'matching', that is, putting social workers and service users together on the basis of race. Humerah declares that what is so good about her present social worker is 'the combination of skills and expertise she brings *combined with* her knowledge as an Asian woman'. Humerah says that the fact that her worker is an Asian female is not the most important factor, but a good Asian worker can make it easier; she can think of circumstances when this might be disadvantageous (for example, if there was an assumption that they were 'the same', or they held fixed views about culture). In fact, they are from very different communities with dissimilar backgrounds in every other respect than the fact that they are both Asian. So, the ethnicity is not the deciding factor, but in this case it has turned out to make a difference.

Humerah has no family involved and there is a 'full stop' as soon as they are mentioned. The social worker 'has accepted my family situation – it isn't an extended family – and she hasn't insisted on involvement'. It is another example of her respecting Humerah's wishes and letting her have control. 'Some social workers are pushing all the time to get your family involved, even when it's clear you don't want it or it's not appropriate.'

There is no timescale to the worker's involvement with Humerah because of the nature of her recurring mental health problems. She sees Humerah about once a fortnight – more when necessary. She coordinates Humerah's care plan and also meets with her therapist from time to time. Humerah explains that her worker used to be a part-time counsellor at a GP surgery and, although she is not doing 'counselling'

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with Humerah, she thinks the counselling skills which the worker brings are a help. 'When I'm very distressed she doesn't push it, just gives me space.'

Humerah has physical care needs, too. Her social worker integrates the physical and mental health care. Humerah talks about how they tried to close her mental health case some while back (before her current worker) and place her with the physical disability team. 'They said, "that's your primary diagnosis, physical disability, and that's the team you have to go to". My argument was very clear that my physical condition doesn't require a lot of care, but it's my mental health condition that makes the roof fall in over and over again.' Humerah had to appeal and meet with the head of services. Her previous social worker had always said that this or that could not be paid for out of the physical disability budget. Humerah became very involved with the detail of budgets and trying to strategise and work round the system, as administered by her social workers.

When she appealed and met with the Head of Services, she asked again about what budget this help and that help would come from. 'They said, "it shouldn't matter to you about the budget" and, you know, that was absolutely right. What's important is getting the care, not who pays for it. That's what *they* are paid to worry about!'

'My social worker recognises the importance of work for me, and her support for me to be able to work is a major plus. She thinks outside the usual boxes when working with mental health service users. By offering support and flexibility that fits around my employment it enables me to retain my identity and sense of self-worth.'

What we can learn from Humerah's story

Humerah's story throws light on many different aspects of good practice. Before you read our commentary below, perhaps you would like to make a list of your own headlines. What are the important messages from your reading of Humerah's positive experience of social work?

Below we present 12 themes from Humerah's story. See how they compare with your own list.

1 Recognising, and resisting, the weight of history

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