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“Ooh where did that come from?” Celebrating systemic practice in services for adults with intellectual disability

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What and whom we choose to celebrate says a lot about us. As I thought about celebrating systemic practice, I wondered about how and when those, with whom I most often practice, men and women with intellectual disabilities, have been celebrated?

We celebrate those things that have importance for us. A celebration of something regards its object with a spirit of honour and respect. People with intellectual disabilities in receipt of health care have, when they have managed to receive it (and they continue to receive a lower standard than the general population), historically been ‘medicalised’, that is, discoursed as ‘cases’. I have a ‘case load’. In fact, I have a rucksack, but these are the everyday multiple realities in which we must make our home... One of these realities is that the history of people with intellectual disability has been one of separation, with shared humanity often forgotten. (See, for example, the many stories collected by Professor Dorothy Atkinson, 2005).

The Pre-Socratics set forth the knowledge of their cultures, initially orally, in the story format. Paul Feyerabend (1994) argued that this kind of narrative knowledge (particularly useful for explicating process rather than the static labelling of lists and tables and so forth) was largely usurped in Western Europe and North America, beginning with the Socrates of the platonic dialogues through to those involved in standardisation/homogenisation of scientific knowledge that characterised the project of Europe’s enlightenment. This may be a polemical view of the enlightenment, however the post-modern revaluing of ‘story’, local knowledge and a humility about what ‘we’ can know about ‘them’ has supported a renewal of the legitimacy of other kinds of narrative knowledge; of listening to the stories of men and women with intellectual disabilities and those who support them.

Everyone has a story to tell. That is, if they can find an audience.

“I never said anything in the hospital because there was no point. Nobody listened so why speak?” (Mabel, R). Atkinson (2005)

Back to celebratory. There are many written and published autobiographies of the rich and famous, but not many of people with intellectual disability. Others have written about them. Men and women with intellectual disability have often actively been silenced – others (people like me) have spoken on their behalf. Examples of people who have written biographies include Joey Deacon, who, with the help of his friends in St Lawrence’s Hospital, Caterham wrote *Tongue Tied* (1974) and Nigel Hunt (*The World of Nigel Hunt: Diary of a Mongoloid Youth*, 1967). With this in mind, I want to celebrate systemic therapy and practice with people with intellectual disability. Systemic therapy is a modality that creates the possibility for the therapist, the person and others significant in her or his life to come together and hear, create, elaborate and celebrate the stories that people bring. I celebrate the shifting discourses that I have experienced using this approach, from referrals that speak of difficulties experienced and problems internalised to ensuing conversations characterised by energy, fun, unique stories and possibilities. When Amanda’s referral form arrived at the Community Learning Disabilities Team (CLDT) from a member of staff at her residential service (people with ID rarely refer themselves), it described the difficulties Amanda experienced with understanding and managing emotions and a perceived need to control others.

We asked:

“Who needs to talk to whom?”

“Who would Amanda like to meet with?”

Amanda chose the manager of the residential home in which she lived. When we met, Amanda told the manager and ourselves that she wanted to be listened to. The home manager, Andrew, talked to Amanda, the team and myself about how he wanted to know more about how to support Amanda and in particular how and when to ‘step in’ when she was feeling distressed. As we listened to Amanda, we found out that she was an expert on this. We found, as we sometimes do, that we didn’t talk for too long about the difficulties and moved quite quickly to talking about how to go on with one another. We talked less about the ‘controlling tendencies’ and more about Amanda’s and Andrew’s dilemmas and hopes in relating. At our second meeting, Amanda and Andrew let us know that two meetings were enough and we talked about how they would spread the news of their new understandings with other staff members. At a six-month follow up interview, Amanda appeared pleased and perhaps surprised that she could be listened to by staff at the service.

“They were alright with me, they listened to me.”

The manager, Andrew reported:

“...I found it quite unusual because it wasn’t someone coming in and just talking at Amanda or talking at me. It was quite unusual that it really was a group discussion... so it was a bit sort of oh where did that come from? I found it great fun.”

Andrew also told us of how the importance of listening had developed further and that a new practice had developed in the residential service where those living in the service had a new opportunity to provide staff with feedback on their support practices.

“I really think it [beginning to listen to her] helped their relationship with Amanda. They saw her in quite a different way ... so I think they’ve changed.”

It isn't always like this. Sometimes the struggles linger... However I celebrate the systemic approach that supports those in relationship to work collaboratively together. Stories are powerful. Stories are resources. Listening to Amanda's and Andrew's stories led to a service-level change. Service workers, paid carers and, of course, family members too, are also not treated merely as conduits for professional knowledge by a systemic approach but rather as experts and partners in the social construction of new possibilities. Their stories are heard also.

Systemic practice has been increasingly recognised as a legitimate option in working with men and women with learning disabilities (See Baum & Lynggaard, 2006). I celebrate this and the opportunities systemic practice can provide to celebrate the abilities, resources and lives of people with intellectual disability and their supporters; that's a lot of celebration.

References

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Permission sought and attained, names and other identifying information removed.