Constructing disability
Disability and learning disability may be contested concepts but disability scholars do concur on one matter: they do not study disabled people or people with learning disabilities; “disability studies is centrally the study of the disabling society” (Swain et al., 2003). At its core is the social model of disability, which is usually contrasted with the medical or individual models of disability. Where the individual model sees a personal tragedy, the social model finds social oppression. Proffering individual treatment is passed over in preference for social action. Self-help and self-expertise succeeds medicalisation and the expertise of non-disabled people. One does not adjust to one’s disability – who but the oppressor themselves would solicit the oppressed to ‘get over it’. The person isn’t the problem…the aforementioned disablement is.

Social change is the goal; and it is disabled people themselves who have been the rather successful driving force in the dismantling of barriers that exclude people with impairments. Disability is created and recreated in everyday life; in the patterns we are all involved in and the stories or meanings we create about ourselves and those we label as dis-abled. Large scale structural – for example – legal changes, while essential, are not enough to change ‘hearts and minds’. If we take this at all seriously, we can begin to see that, as systemic therapists, we can have a role, if we so choose, in challenging disabling cultures.

What, though, of ‘incredulity toward meta-narratives’ (Lyotard, 1984), a position of skepticism of those large stories that purport to be the lens through which social life is interpreted? The social model (‘the oppressed’) is strong on rights but can discount the experiences of individual disabled people, and their secondary health problems. The moral model of ‘the chosen’ – associated primarily with Judaeo-Christian culture – may invite pity but may also be seen as strength by some clients who understand themselves to be chosen by a God who recognises in them the strength to bear this burden. The humanistic model or the ‘human being’ views disability as part of diversity but risks ignoring differences in experience and oppressive social relations. The ‘crips’ or cultural model views disability as a proud culture but may invalidate therapy clients who do not experience themselves as such. Roosen draws these understandings of disability together to propose that a rich diversity of understanding that does not reject out of hand any of these positions will allow therapists to take a more flexible, informed and positive approach to disability.

Systemic practice in services for people with learning disabilities – a referral may be a sign that disabling processes are being enacted
What kind of work does one engage in as a systemic therapist? Well, in terms of disablement, in therapeutic work with adults with learning disability one may meet with those who have greatly reduced opportunity to exercise choice/have power in their lives, have been bullied and beaten up, who do not have enough money to engage in everyday activities most of us take for granted, who have no work, or who are victims of supposed ‘friends’ who

Disability being socially constructed: The label we must drag around with us by Andre Jordan.
may have exploited them in a variety of manners.

“As more individuals are given the chance to live independently, the unwelcome side effect is that they are more likely to fall prey to criminals” (Williams, 2010).

Such reporting in the press of the abuses of people with learning disabilities – in this case of so called ‘mate crime’ – is undoubtedly to be welcomed. Can one detect, however, a narrative informed by tragic, individual models of disability? Falling ‘prey’ to criminals is not a side-effect of being ‘given a chance’ to live independently. This risks presuming victim-hood as a symptom of impairment. It might be equally considered a side-effect of disablement; for example, perhaps of a human service system that has kept people outside of their communities and natural supports for more than a century, only to subsequently offer inadequate support for them to take a place once more? For many – but of course by no means all – people with learning disabilities, it seems there is not yet a full place for them in their communities, where they may face long-term unemployment, reductions in day services and college placements and a diminishing input from social care services. Of course, we can’t solve all the above issues. We can, however, work with the effects of problems being constructed as if they are a side-effect of impairment; explore ways in which disablement (and enablement) are part of the day-to-day life of the person; explore structural barriers such as inaccessible information and poor quality support services, barriers to adequate healthcare, as well as making visible dominating stories – perhaps informed by models – of disablement in play in a person’s/system’s life. We can as family/systemic therapists act to bring people together and support them in resisting disablement in a strength-based conversational context.

**Referrals**

When residential and day care services refer people with learning disability to the community learning disability team, they are often seeking help for a problem they perceive their client to have. As such, clients may be at risk of being seen as ‘problem-saturated’ (White & Epstein, 1990). This view of the client may make unintelligible more useful understandings of the client and their relation with the ‘problem’. These problem-saturated descriptions may, like the wider culture, reflect tragic, individual models of disability. Challenging behaviour, for example, may be discoursed as emerging from impairment itself (Goodley, 2001) rather than a social-relational artefact.

This is an extract from a referral form to a community learning disability service taken from a study by Nunkoosing & Haydon (2008):

“[I am] verbally aggressive toward other people. [I am] unwilling to listen to reason. I can be very bossy, often involving myself in other people’s affairs that do not concern me.”

People with a learning disability are most often referred by others. The referral will often reflect the concerns of someone other than the person. In the above referral the person’s voice is seen here appropriated in a perversion of person-centredness. Person centred planning (Cambridge & Carnaby, 2005) is an approach to life planning that places the person’s goals, hopes and dreams in the centre of a process completed by a circle of support that will work to make these a reality. As systemic therapists, we are well placed to support new ways of seeing people as separate from problems. When we engage in discourse, we do so in place, time and culture. There is quite a bit of ‘back stage’ (Goffman, 1959) talk in any organisation. In community learning disability services, these include staff meetings, referral meetings and supervision. Erving Goffman – an acquaintance of Bateson’s and sorely neglected in contemporary writing – described backstage performances as those undertaken without the audiences of, say, other organisations and customers/clients present. These performances of self may consist of conversations that would not be seen as appropriate in front of the ‘audience’. Within contemporary services, you might stumble upon backstage use of shorthand terms such as ‘perp’ and ‘victim’. Sometimes, such ‘backstage talk’ is overheard by the audience. In a study of parental experiences of learning disability service providers, a focus group included descriptions of contacting services over the telephone:

Viki: “You can hear when you say your name, you can hear your name going all round the office because they’re trying to work out who’s going to talk to you that week”.

**Laughter in the room**

Viki: “They’re like no we don’t want her, no I had her last week, no I don’t want her”.

Angela: “No, they’re always in a meeting or they’ve just stepped out or they’ll call you back”.

Sharon: “They’re on holiday and they’ll be back next week”.

Wikins (2010)

There is an inevitable, and not necessarily discreditable, rationale for the idioms of backstage – ‘it’s just shorthand’ or ‘semantics’ – as if pleading a temporary liberation from the weight of our words. The explanations may well be sound but Foucault warns:

> “By casually doing something as simple as naming a person, a child, we might be putting on lids and casting shadows on their power”.

For Goffman, those who are not present at a performance are ‘off stage’, and may or may not know it. People with learning disabilities are off stage when professionals and other paid service workers get together and discuss people with learning disabilities in their absence. This may be at meetings to investigate possible incidents of harm to ‘vulnerable adults’ or when in some consultations with support staff only. Work without the person is something that occurs regularly in services – often the rationale is that the person’s perceived cognitive deficits limit the possibility for inclusion. I still find it troublesome. However, in order to challenge disabling processes, I have found it, at times, useful not to work with the person directly; in order to begin an
systemic practitioner, I began to understand that I shared responsibility for these stories. For one thing, the conversational format of my meetings with staff and families were scripted, practiced, a ritual. The clinician asks for information and then provides advice, guidelines and so on. When I met the team who had referred Tanya, they were caring, open and experienced. I felt they must ‘know’ so much more about this woman but appeared to struggle to tell me about her. They agreed to some internalised other interviews as a way of creating ideas. I interviewed the internalised Tanya ‘in’ the manager and did so in front of the large staff team who reflected together on the interview afterwards. Following the reflections, I interviewed the manager as himself about the reflections and the experience as a whole. This was the first meeting with staff I had been a part of that included expressions of emotion and thick(er) descriptions – a deeper conversation. There was some energy in the room and the team and manager were excited by what they had known of the person and yet this information was also somehow new to them. From this initial interviewing the internalised other we developed other ideas about Tanya’s experiences and how we might develop plans to support and include her more effectively.

Using this approach, I found that conversations that began with internalising and denigrating descriptions, following interviewing the internalised other, developed quite a different tenor. I have found staff have begun to notice barriers clients face; felt pain they may have experienced; experienced a greater sense of their experiences of the client’s experiences. Staff can face barriers too and this work is empowering for staff. We have begun to talk of disabling aspects of service approaches – without me having to convince them of it. Possibilities have more generally shifted from those that highlight a need for a disciplining response to the client to those that highlight a need for support, care – understanding.

Systemic techniques such as interviewing the internalised other have been useful in my practice to impact disabling processes and meanings in supporter-client relationships. Used in this kind of context, it can have a disruptive effect on toxic stories of people with learning disability. This use of it may be conceptualised as not seeking to act upon the person or their supporters, as such, but rather on the discursive environment creative of disablement.

Using and refusing

“I’m thinking that disabled is not the right word. I’m thinking that you’re still a human being that... we are put on this world to be loved and cared for, not to be called names... labelling should be banned completely, right off, scrub it right in the bin, the scrap heap” (Palmer et al., 1999, p.36).

Conversations about the rights and wrongs of labelling continue in services. A label offers certainty. Acceptance of a label constitutes a false consolation, a false consciousness. A label excludes a group of people, enables society to practise vigilance over them whilst simultaneously offering access to a community – of labelled others (Migerode, 2010). A label may offer access to resources whilst it regulates the identities of disabled people forced to accept prescribed ‘client’ identities (Goodley et al., 2008). A diagnostic label offers a message to others in the community that the family/parents are not failing, that they have a difficult task with the labelled child. A diagnosis allows a clinician to stay closer to people’s experiences (Migerode, 2010). A label can lead to monologue as one member of a family (the person with the label) is viewed as a stressor that the others must adapt to and cope with (Rober, 2005). Labels may be part of the process of discovering the
level of the person’s disability and whether any associated conditions are present so that ‘needs’ can be better met, specialist services accessed. Families struggle to negotiate the meaning of labels. In relation to diagnosis – IQ testing for example – how often is there serious consideration given to the managing of meanings associated with the achievement or non-achievement of a new label in a person’s life?

For Ágústsdóttir (2010), the ‘why do they do’ of a label is “to be in a better position to address individual needs” whilst the ‘what they do does’ is rather to “remove the responsibility [for disability] from the society and put it on the people that have been diagnosed”. Ágústsdóttir is one such labelled person. I take issue with Ágústsdóttir of resisting disablement or explore contexts influencing the construction of the problem such as agency task definitions.

Conceptualising abilities as existing in individuals is an atomising practice that privileges the individual over relationship, categorising some members of our society as incompetent. IQ testing is an emblematic example of an atomising practice. Competency can also be understood as created between people. This has been described as ‘distributed competence’ (Booth & Booth, 1998). Of course, this notion has direct resonance with systemic practice but is nevertheless an aide memoire to keep a focus on the potential competencies in a person’s network. Have a look at the following vignette.

Amanda and Josh
Picture a therapy session with a couple and their adult son and daughter, Amanda and Josh (the identified client with a diagnosis of depression and labels including challenging behaviour). Josh doesn’t say much as Amanda talks about the family. Josh appears interested in his i-phone. Amanda tells me that Josh is interested in technology and that they talk about it in the evenings. When the reflecting team come to speak, they talk of the smallness of Josh’s ‘voice’ in the family; one member feels that the daughter holds all of the space in the family. Might the daughter feel the need to occupy some space in the family as she may have felt that her brother has taken the time of the family due to the focus on his disability?

The concerns in the team fit an individual tragedy model of disability; to the extent that competency in the family is understood as a discreet property of each person. Distributed competence asks us to explore what it is they achieve together. We see that the brother programs the electronic devices for his sister – it was her i-phone – that help her to remain socially engaged (if you consider using
people with learning disabilities require levels (Shakespeare & Watson, 2001) and disabled people as: disabilities and may be viewed by many of intervention in the lives of people with disabilities and may be viewed by many disabled people as:

“Pathologising, voyeuristic, individualising, impairment obsessed ... contributed to the exclusion of people with impairments” (Goodley & Lawthom, 2006).

Intervention is required at multiple levels (Shakespeare & Watson, 2001) and people with learning disabilities require rights-based social activism to change the societies in which they live, effective medical intervention to support their physical needs as well as support that encourages psychological and emotional wellbeing whilst acknowledging and responding to ablest culture. Amanda and Josh remind us that systemic practice, if not vigilant, can speak from an atomising context.

Shakespeare & Watson (2001) suggested that disability should not be assumed to be the key to a person’s identity. I will risk sounding complacent to suggest this is not an assertion that should present too much of a challenge to systemic therapists. Disability studies use the term disabled people to highlight the social processes that are disabling of people with impairments. People with learning disabilities want to be people first and there are good reasons for this. People with learning disabilities have often had their disability closely entwined with the idea of damage to the integrity of their personhood.

Disabilment and systemic therapy

Given the historical over-reliance on medication and behavioural psychology in the context of deeming social constructions of disability, systemic work may offer a fruitful therapeutic alternative. Many of the practices I undertake do not reflect powerfully supported categories of dis-ease such as the various ‘mental disorders’, do not employ codified practices such as manuised ‘couple therapy’ or reflect the categories of funding in payment by results. In the current mono-cultural medicalised therapeutic climate, it is uncertain how long such practices will survive.

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References


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