# Disablement, systemic therapy and people with learning disabilities

## Mark Haydon–Laurelut

I work a part of my week in a number of community learning disability teams. I undertake family therapy and systemic practice of various kinds including with the staff and management of support services. The remainder of my week, I work as a lecturer at the University of Portsmouth. This paper explores some ideas about disablement and some of my experiences of working systemically in services for adults with learning disabilities.

### 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 (if indeed it is a 'model') appears a candidat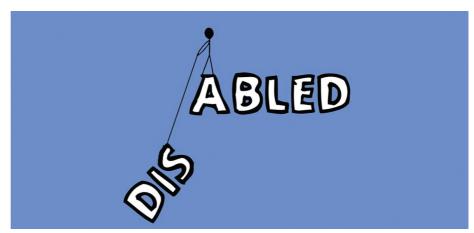e for incredulity? Critical disability-scholars have begun to expand thinking beyond a single model that might explain disablement. Disability, as much as identity more generally, is found to be fluid, uncertain and unstable (Shildrick, 2009). Reifying definitions of learning disability are, in this context, anachronistic.

Roosen (2009) offers possibilities for therapists. Disability has often been viewed in the psychotherapeutic literature as a pathologised condition leading to a maladaptive personality and poor social functioning. Roosen offers a trip through other characterisations that may be drawn upon. The medical take on disability is characterised as the 'broken person'. Medical understandings, though important, may lead to deficit-saturated constructions if they are the dominant source for conceptualising disability. 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 disability 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 & Epston, 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".*
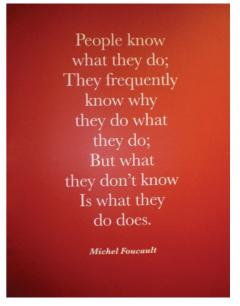
## Laughter in the room

**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:

People know what they do; They frequently know why they do what they do; But what they don't know Is what they do does.

**Michel Foucault**

Above: Photograph taken at Museum of Slavery, Cape Town, SA

Aimee Mullins (2010) speaks of the act of naming and its impact on herself as a disabled person:

*"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

investigation into the social creation of problem meanings in the service system and professional network. With regard to this work, Rikberg-Smiley (2006) usefully asked *"Who needs to change?"* An additional reason I may not work with the person present at a particular meeting is when there is good reason to believe that workers may speak in a denigrating way about the person, particularly if there may be a number of people who may speak like this. There is a tension here in that this practice appears to be out of synch with person-centred ways of working and slogans of disablement such as 'nothing about us without us', but the notion of working on disabling culture – the guy with the rope – leads to consider further flexibility.

Referrals and the talk about them can be read as concerned with locating responsibility for actions and the creation of social identities. These are not the explanations that would be voiced but they might be *"what we do does"* as we *"turn real lives in writing"* (Foucault, 1977. p.192). New actions are formulated on the basis of these. This talk, in the context of a referral for difficult behaviour, can often be problem-saturated and blaming of the person. Conversations can also be excusing of the person with recourse made to the person's disabled status and imputed characteristics of passivity, incapacity serving to locate responsibility for actions of the person elsewhere; 'in' the disability or 'in' the family (e.g. family members – very often so called 'over protective' mothers). See Juhila *et al.* (2010) for an illuminating account of backstage talk in supported housing for people with mental health and substance abuse problems and 'troublesome' behaviour.

## Systemic practices, social theory and adult learning disability teams

### Interviewing the internalised other

When I first came across systemic ideas, interviewing the internalised other (Tomm, 1999) was one of those that excited me the most. I often worked with people with labels of severe 'learning disabilities' and 'challenging behaviour' and they told us about themselves through behaviours such as harming themselves, hiding themselves away from others or damaging the objects around them. Some of the stories I heard about clients were at best thin and functional; at worst blaming and pathological. Some stories spoke of anger

and fear of persons and some supporters were simply finding it difficult to envisage what life might be like for the person and had a yearning to understand more.

As a systemic practitioner, I began to understand that I shared response-ability 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. Interviewing the internalised other along with other practices such as externalising, reflexive questioning, reflecting teams, the dialogical approaches of the Public Conversations Project (where problem solving was banned for a portion of the meeting and a focus on hearing all voices was enforced by yours truly) were exciting new territories to me and offered me a way of taking some responsibility in creating new, more possibility-filled, stories.

### Tanya

*I began to use interviewing the internalised other when working with a person who had a label of severe learning disability. She was referred to me for hitting those she shared her home with. Like most of the people I worked with at the time, she had a huge file and had had lots of input from many professions. As it tended to be with these files, there was no sense of her – let's call her Tanya – voice. 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 Ágústdóttir (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 Migerode's (2010) somewhat quixotic stance. There are many meanings that may be made by others concerning a diagnosis of autism, of which the parents having a difficult task is only one. Many of them, I suspect, may be less gracious. Diagnoses may be a step towards the experiences of some but they are likely to be the experiences of those with the power to label rather than those to whom it is attached.

The notion of supporting people to both use and refuse labels (see for example Butler, 1990 & 1993) appeals.

Might we ask:

*"Will you drop this label when the kids have grown up and you don't need the help anymore? Or is there something you'd like to hang onto?"*

*"How could this label of 'vulnerable adult' help you here?"*

## Disability liability: Who should accept disability?

Some parents of people with learning disabilities, when viewed as troublesome, are accused of not having 'accepted' their son or daughter's disability. A study by Almack *et al.* (2009) found that parents negotiated their way through identity positions of over-protective or neglectful at the time of transition from child to adult services, whilst understanding their son or daughter to be vulnerable.

If disability is socially created, we must take care with this construction of acceptance. It becomes oppressive to 'support' those oppressed with disabilities to 'accept' their oppression. This is the oppression of supporting people to 'cope' with disability. Resilience is a

much-used discourse in both clinical, research and wider managerial contexts. Resilient, flexible, responsive – elastic. The organisation, profession and administration demand the individual possess these attributes; all the better given what individuals will be exposed to by these institutions. This neo-liberal concept places responsibility for change on those experiencing exclusion. This appears to be very much tied up with the location of responsibility/blame when the work with a person and their network is not going smoothly. What kinds of questions might emerge from this kind of thinking?

*"Why should they accept the disability?"* (What authority have we given ourselves that enables us to request they do so?)

*"How do they show you they haven't accepted the disability?" "What else might this be an invitation to?"*

*"How would you know the parents had accepted the disability?"* (Perhaps they might agree with our frame of what a disability constitutes?)

Ágústsdóttir (2009), in writing about growing up with cerebral palsy, describes:

*"I was a child and of course I had no premises to belittle myself or think I was something less capable than others. The society with its powerful messages was, however, quick to show me the ropes".*

She continues in relation to acceptance and adjustment:

*"I have not had to forgive or make peace with my disability, because I have not been discontent with it. The attitudes of society have however caused me great distress and I have had to forgive society a great deal".*

As a disabled woman, one method for Ágústsdóttir of resisting disablement and the invitation for its acceptance is to *"provoke by being sexy"* (Ágústsdóttir, 2010).

## Accountability, distributed competency and the institutional creation of 'challenging behaviour'

Working with a critical disability studies orientation leads us to put to the foreground issues of accountability. If problems are socially made, social resolutions follow in an ethical therapy. Many people I have met are viewed as challenging simply because they do not meet agency expectations, for

example, ideas of independence. More 'independence' may also be connected to 'less support' and contradictions are created for people. In support services, those not meeting targets for skills-teaching may come to be viewed as problems and referred to community learning disability teams. The team can join with the problem definition and try harder to fix the problem/person 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

facebook and texting to be so) – and she helps him with the talking at meetings and introducing him to new people in his life.

## Discussion: Disability and therapy

Systemic, or any other kind of therapy, is not a cure for learning, or any other kind of disability. It should not become a response to the 'problem' of disability. I mention this perhaps somewhat obvious detail as we as therapists with an eye to social justice must be clear that therapy of any kind cannot stand in for other kinds of action, be it medical, socio-political or otherwise. For many in disability studies and the disabled people's movement more generally, clarity about our position is important. Psychology has a long and ignoble history 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 ableist culture. Amanda and Josh remind us that systemic practice, if not vigilant, can speak from an atomising individual model. Systemic therapy cannot change dominant discourses of disablement but it can support people and their significant networks of kin and friends and services to take different positions in relation to these.

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.

## Disablement and systemic therapy

Given the historical over-reliance on medication and behavioural psychology in the context of denigrating 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 manulised '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.

## Acknowledgement

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Mark Haydon–Laurelut works for the University of Portsmouth & Sussex Partnership NHS Foundation Trust.

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