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Disability: Beyond individualization, psychologisation and medicalization

Mark Haydon-Laurelut

“Medicine finds a home everywhere”

(Michalko, 2012)

We usually tell our students, “you should keep in mind

24 hypotheses, 50 stories” (Cecchin, 1992)

Disability: A story of a problem seeking solutions?

Knowledge about disabled people has and continues to be dominated by the medical and allied professions and inevitably this provides only one story of disabled life: a story of a problem seeking solutions (Grue, 2015). The rehabilitative professions write most of what is read and written about disability. As a family therapist I wondered how family therapy might be constructing disability? If, as Michalko (2012) has noted, medicine finds a home in all kinds of places to what extent has it made family therapy, and in particular its conception of disability, its home? Haydon-Laurelut, Nunkoosing & Wilcox (2015) found that contemporary family therapy journals frame disability predominantly through an individual medical model. This is perhaps unsurprising as it is reflective of the cultural dominance of this narrative of disability (Oliver, 1990). Haydon-Laurelut et al (2015) suggested that disability might have become so penetrated by medical discourse that it becomes difficult to see it outside of this frame. More evidence is required on this issue

however these findings raise questions as to how systemic therapists engage with disability. This paper draws upon the finding of the study that the articles analysed almost without exception failed to demonstrate knowledge of disability studies. The paper will therefore introduce concepts from disability studies and explore how they might support a therapeutic practice with disabled people, which goes beyond medicalization. The foundational model of disability studies is the social model of disability (Oliver, 1990). The social model emerged from the disabled peoples movement and advocated the notion that disability was something that people with impairments had imposed upon them. These were termed “barriers”. For example, a building with a door that is too narrow to allow them to enter disables a person who uses a wheelchair. A person who has a cognitive impairment is disabled by a therapy that consists of questions too complex for them to benefit from it. It is this stance that leads to the use of the term ‘disabled person’ rather than person with a disability. The person does not come ‘with’ a disability; societal barriers to full inclusion disable the person. The social model makes the important distinction between a person’s impairment and disability which it views as the restrictions of activity placed upon the persons (hence the disabled person) of a society that takes account of only some of its citizens. So disability, for the social model, concerns the difficulties people with impairments face when they attempt to take their place as citizens. However the social model (as is the case with all the ideas of disability studies presented in this paper) is a product of both academia and the social and political movement known as the disabled peoples movement (UPIAS, 1976). These are powerful and important ideas in particular contexts. However, as Cecchin implies in his quotation (above), in the context of systemic therapy, one story will not do. Ideas from social theory may not be intrinsically more useful than medical ideas and the context of the individual therapy conversation must be acknowledged. The paper will return to this issue in the section on considering and coordinating disability-stories.

Building on these foundations, critical disability studies employ a broader range of social theory to re-conceptualize *“disabled bodies and minds as*

social sites of power, language, discourse and action" (Goodley, Hughes & Davis, 2012 p. 5). The shift is from disability as located in individual bodies to disability as a social space that may be analysed from many disciplinary locations (sociology, psychology, geography, legal studies and so on) and many theoretical positions (psychoanalytic, phenomenological, discursive etc.) [i]f we understand disability as a social artefact then this suggests disability may concern all of us and that disability might be understood not as a knowable object but as an interpretative space (See Titchkosky, 2003). In this way critical disability studies offers opportunities for professionals to be part of conversations that trouble hegemonic (tragic, individual, medical and so on) stories of disability. Let us consider the inherently social concept that is Disablism. Disablism has been defined as:

"A form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well being" (Thomas: 2007 p. 73).

The concept of Disablism allows us to place disability outside of purely medicalised discourses. Disablism in therapy might be: a therapist's assumption of the meaning of impairment for a client (for example as a tragedy in their lives); it might be physical restrictions in access to location of the therapy (for example the requirement of the client who uses a wheelchair to enter through a "side door"); it may take the form of a cherished therapist story that psychological difficulties will be intimately related to a particular impairment rather than, say, to the experience of Disablism). In this way we can see how disablism and disability itself is socially made and may be made in therapy as Goodley notes: "*dis/ableism and impairment as being naturalized in institutions of schools, long stay hospitals, clinics, universities, community groups, rehabilitation centers and families*" Goodley (2011 p. 162). Disability and dis/ableism (Goodley uses the composite term dis/ableism as a way of drawing on studies of both disablism and ableism which is addressed below) highlight the productive possibility of engaging in the interrogation of administrative and professional practices. In other words we might ask

ourselves in our research, clinical and administrative practices questions such as:

How does family therapy construct disability?

How do our agencies, professions and clinical practice reproduce disability and disablism?

Ableism

Whilst disablism usefully highlights the oppression of disabled people, ableism invites us to attend to the kinds of bodies that are valued. Ableism has been defined as:

“A network of beliefs, processes and practices that produces a particular kind of self (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability is then cast as a diminished state of being human”.

(Campbell, 2009 p. 5).

Ableism is a more inclusive concept than disablism. It recognises that we will all struggle to attain the valued body, the species-typical body of the moment. For our neoliberal “moment” this is the autonomous, rational, employable, (narrowly conceived) economically productive individual. This individual (and one must consider that characteristics of race, class, ethnicity, sexuality and so on will make up the Ableist ideal as western, white, middle class and so on) risks excluding most people with intellectual disabilities and moreover puts into question the status of anyone requiring support or help of any kind. Ableism also raises questions about identity politics and the use of the cultural category of ‘disability’ - formed by a disabling society - as a basis for the struggle for equality. Though the progress of the disabled peoples movement has been undeniably impressive identifying as “disabled” and employing the concept of disablism continues with the logic of “them” and

“us”. These are questions that are not by any means settled. Let us consider some questions Ableism might raise for therapists.

As therapists we might ask:

How can we interrogate ableist normativity, the notion that the ableist ideal is always axiomatically preferable to being a disabled person?

How might we consider the influence of ableist discourses in the therapy room?

To be more specific, in my agency context of community learning disability services in the UK I might ask:

What’s wrong with dependency? Who wants to be “more independent” and from what? How are we being organized by this idea and who benefits from the idea that to be dependent in some way is to somehow be less than fully human or in need of cure or rehabilitation?

Why is it better that this person speaks when they sign/use a communication aid just fine

How fast should a person be able to think?

Why is this person seen as more vulnerable because he relies on the help of someone else? What assumptions are framing this meaning? Can we not view what he is able to do as being something that exists in relationship with others?

More generally, Campbell (2009) asks how can we move past the implied question:

“How do you manage not being like the (non-stated) us?”

(Campbell, 2009 p. 15)

Part of the power of Ableism is that of course none of us meets the ableist ideal yet we may fantasize that perfection exists. These meanings create the groundwork for viewing clients as in need of cure rather than sharing in the “woundedness” that is our shared human condition (Game & Metcalfe, 2010).

As therapist we might wonder:

“What ideas or fantasies of the perfect family are most troubling to you?”

And as therapists we might ask ourselves:

“What fantasies of the perfect therapist (and how they should work with disabled people) are organising my experience of practice right now?”

These are not new questions for family therapy, however ableism invites us to frame these questions in the contexts of internalised ableism in family and professional life. Let us consider some further concepts that may support our work as family therapists in opening up dialogues of disability.

Normalcy and Normative Shadows

What becomes for us normal and natural? How are they intertwined with the differences that get viewed as abnormal and unnatural - or disabled? Intellectual Disability, impairment categories such as “Autism” and constructs such as inappropriate or “challenging behavior” [ii] (Emerson, 1995) are often highly visible in services. “Intellectual ability” or the “learning abled”, “non-disabled” and “Neuro-typical” are more often less visible. In the community services in which I work, the idea of “normal” behaviour is implicit in many conversations indicated by euphemisms such as “independence”, “skills” and the need to be “appropriate”.

Amy [iii] (a person with a diagnosis of intellectual disabilities) has given her permission for me to share a brief excerpt of the work we did with such words. It is important to note that seeking capacity, in the UK context, must

comply with the principles of the Mental Capacity Act (2005). This stipulates that a person is assumed to possess capacity until shown otherwise, that capacity is understood as being in relation to a particular decision (it is not a global stable state) and that the responsibility is on the assessor of capacity to make all reasonable adjustments to make present the salient information regarding a particular decision as accessibly as possible. With people with intellectual disabilities this may for example involve chunking of information, using pictures as well as words and providing enough time to support the persons ability to comprehend, hold in mind and synthesize the information in a way that enables them to make a decision. Where the person is found not to have capacity a decision may be made in a person's best interest and the act and accompanying guidance provides information about how to go about this.

The manager of the residential service in which she lived referred Amy to me. Amy was referred because of behaviour that was described as challenging to those with whom she lived at the residential home. During one a session I had with Amy she used the word "appropriate" a number of times. I asked Amy about this and she told me it was a word used by the manager of the service. I asked Amy if we could draw a word spider or linguagram on the white board:

Mark: "So John (manager) wants you to be more appropriate?"

Amy: "Yes"

Mark: "Amy, what words come to mind when you think about appropriate?"

Amy: "Sensible"

Mark: "What word comes to mind when you think about the word sensible"

Amy: "Normal"

Mark: "... Who is most worried about all this?"

Amy: “I’m not worried, they are worried”.

In a small but important way we had scrutinised the service language that for Amy concealed her experiences of others wanting her to be closer to an idea of normal. The work with Amy came to a close fairly shortly after this conversation as Amy decided that she was not a customer for change at that time but that there were things about her life she wanted others to understand and which we shared via a letter.

When we make disability we also make normalcy [iv]. Normalcy is not something that is merely imposed upon us, we re-create normalcy moment by moment in administrative, personal and professional practices including in therapy.

Consider this statement to a mother of a child with intellectual disabilities.

Therapist: “You are coping well with Amy”.

What might be the Normative Shadow here? Perhaps "normal" families do not have persons with intellectual disabilities in them and having a person with intellectual disabilities in your life is a biographical disruption and a source of stress with which one is required to cope. You are coping well (after Campbell, 2009) considering your daughter Amy is not one of “us”. If a screening questionnaire for intellectual disability asks questions such as: “does the person need support to attend health appointments”; “does the person have someone who does much of the speaking for them at health appointments”; “do they drive” and so on, then the shadow of this may be a construction of the intellectually abled as human beings who drive alone to the General Practitioner. If someone does accompany the person to the GP, the intellectually able person ensures that this companion doesn’t say too much during the appointment. Here we can see how disability (after Goodley, 2011 above) and ability are made in institutional contexts such as health/welfare and therapy.

So as therapists we might ask ourselves:

"What are the normative shadows of the work, the story, the question or technique I am employing?"

Considering and Coordinating Disability-Stories

What are the implicit or explicit stories of disability that inform its taken-for-granted reality? How can we, as Cecchin (1992) suggests, create more stories through which we might connect with those disabled people who seek our help?

Let us consider that different positions are offered by different discourses of disability. For example, medicalising disability may lead to conversations that focus on "fixing" the person who requires cure or amelioration of impairment. When the medical discourse dominates our frames of disability it may limit opportunities to consider the impact of dis/ableism on experience. However the social model of disability may invite conversations about "disabling society" (Oliver, 1995) and lead to conversations that focus on the "broken society" (Roosen, 2006) or the oppressors "out there" perhaps limiting space for self-reflection and conversations about struggles with impairment - with, say, the experience of pain. For systemic therapists, adherence to any single story of disability reduces flexibility and usefulness to the client. As family therapists the complexity may grow exponentially. For example different stories of disability in a family may contribute to difficulties for example when "care" is given by one family member to a disabled family member in a way that fits with an individual tragedy model of disability, emphasising vulnerability and the need for others to do "for"; another family member may experience receiving well intentioned "care" as invasive; other family members may view it as patronising. Furthermore, psychologised disability-stories may organise therapists to find unhelpful meanings in therapy. For example a client's anger may be framed by a therapist as part of a bereavement process. This framing may lead the therapist to hypothesise that the client

Is processing the loss associated with disability. The client however may be connecting to a social model story of disability that emphasises the importance of activism and struggle and thus frames anger differently, as a response to a society that disables people with impairments. If unexamined these differing stories may make coordination difficult. Noticing the disability stories held by a family and by a service supporting the family may be useful if there are difficulties in the family/service relationship. For example family members may experience the professional systems story of the importance of “independence” for people with intellectual disabilities as a cause for concern if the family is strongly organised by vulnerability stories with a focus on care and safety thus encouraging coordination difficulties in the family/professional relationship. A family offered a “non-expert” or partnership approach that seeks out the expertise of the person and family members may lead to confusion and disappointment if there is a strong family story of disability as a medical issue and the domain of experts who provide information and treatment. With disability being such a polysemic term, creating a space to talk about these disability-stories both within agencies and with families may be a useful support to co-ordination.

Having said this there is little doubt that the medical discourse (or "model") of disability is the predominant way of making sense of disability in contemporary neoliberal capitalist culture. What does this disability-story do? Titchkosky (2003) alerts us to the issue that all of the busy work of defining, measuring and fixing disability has left “us” with little time to understand it: certainly very little time to learn from it. This disability-story sees disability as something to be fixed, eliminated, as a mistake. So we might ask, as Titchkosky does:

What might we learn if we saw disability as a teacher?

What would open up for us if we sought to learn from it rather than about it?

Even a moment’s reflection suggests we might learn (conceptually) how the concept itself props up normalcy and the ableist ideal, how it is the

shadow that brings into being the “normal”/species typical body; we might learn (experientially) about different embodied experiences of the world. We might learn much about the much-quoted psychological concept of “resilience” from those who have survived and perhaps thrived in disabling societies? This may not happen if we continue to view disability as primarily a deviation from a valued norm.

However as therapists should we not honour the utility of medicalised and diagnostic stories have for some people with whom we meet? These disability-stories may offer certainty and relief from wondering “what’s wrong with me”? In my work I have sometimes found it useful to explore with the person and or their networks the uses and drawbacks of these ways of understanding life. For example a person I worked with found the label of Asperger’s Syndrome had helped him to feel less blameworthy for behaviors that had been labeled by services as connected with his personality. He found some safety in the label and sought out services that he felt understood the syndrome. He believed that if services understood Asperger’s syndrome the historical institutional abuse he described to me would not occur again. As he said to me he was “ill” - not “bad”. However understanding himself as “ill” had other implications including encouraging a lack of responsibility for his own (potentially risky behaviour) and the abusive behaviours of others towards him were framed as being the result of lack of education about the syndrome and so seemingly less blameworthy. If medicalised meanings of disability are relativized as one meaning amongst other possible meanings this may invite therapeutic conversations about these stories and what they produce.

Resisting Individualisation

Critical disability studies invites us to pay attention to the ways in which professional practices, concepts, as well as lay/folk knowledge about disability works to produce problems located in the mind or body of disabled people. As an example of this process of individualisation let us consider the term challenging behaviour.

In intellectual disability services (and services for elders) in the UK the term “challenging behaviour” was originally conceived as behaviours that services find a challenge: this is inherently relational. Over time however services talked about people with challenging behaviour or people who have challenging behaviour or who “display” it without reference to the service context in which it occurs i.e. those who find it challenging. Challenging behaviour has fallen prey to individualisation. So disability and those concepts associated with it can come to be located in the bodies and minds of disabled people - divorced from the social context in which they occur. “Resilience” is predominantly conceptualized in psychological terms (Runswick-Cole & Goodley, 2013) as an individual’s response to adversity. Alternative, less individualizing, accounts of resilience can be created and indeed Critical Disability Studies scholars Runswick-Cole & Goodley (2013) have worked with self-advocates with learning (intellectual) disabilities to redefine and relocate resilience as relational phenomena. The extent to which a person has resilience is related to the relationships and their associated resources, i.e. the community within which she is embedded. Working with notions of distributed competence (Booth & Booth, 1998) or what people can do together, presents a challenge to a contemporary culture that fetishizes “independence” and autonomy over connection and relationality. We might ask: *To what extent do our agencies, professions, and practices encourage a view of the person as a burden, a stressor and persons more generally as “atomized”?*

Nunokoosing speaks about individualisation when he reminds us of the profound sociality of bodies: *“you simply can’t be a person with learning disability on your own”* (2011 p. 6).

Conclusion

There is some emerging data (Haydon-Laurelut, Nunokoosing & Wilcox, 2015) that disability is still considered primarily through a medical model lens in the family therapy literature. It may be difficult to “see” disability apart from

the medicalised discourses that dominate our present western culture. Responding to this, the paper described some concepts from disability studies, namely the social model of disability, and critical disability studies, including Ableism and Disablism. The paper engaged in a tentative exploration of the possibilities these ideas may bring for systemic therapy not least in supporting the possibility of foregrounding the socially constructed aspects of disability. There is clearly much work to be done and we can surely draw upon many theoretical and practice traditions as we trouble the individualized, psychologised and medicalised hegemony.

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<http://disabilityuos.wordpress.com/normalcy-conference/>

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[i] For an introduction to critical disability studies see Goodley (2011).

[ii] Challenging behaviour has been defined as “Culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities”. (Emerson 1995, p. 4-5).

[iii] Permission sought and gained and names changed.

[iv] This term is similar to Ableism and has developed separately in differing areas of academia.