

Family Therapy and Dis/ableism: Constructions of Disability in Family Therapy Literature

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Abstract

Family therapy has taken on board issues of human diversity such as race, gender, and poverty in its theorising and practise. We wanted to know more about how disability is constructed in contemporary family therapy literature and what are the discourses that family therapists draw upon when writing about their practices concerning impairment and disability? We reviewed four peer reviewed family therapy journals, published during 2010 and 2011 for articles about disability. Thirty-six articles were analysed and interpreted by means of Critical Discourse Analysis. Whilst the findings suggest that these papers are predominantly informed by a medical and personal tragedy discourse of disability, the articles also drew on a broader range of social discourses. Our interpretation of the data suggests that critical reflection is required concerning the theory and practice of family therapy with disabled people. Engagement with dis/ableism may enrich understandings and support access to a wider range of stories of impairment and disability.

Introduction

Family therapists have shown a committed willingness to address issues of diversity and power, such as the seminal works of the Just Therapy movement (Waldegrave & Tamasese, 1994); the challenge to racist assumptions in therapy (McGoldrick (1994) & Wallis and Singh (2014); the development of contemporary approaches to lesbian, gay, bisexual and transgendered work (Reynolds, 2010) and guidance for engaging with social difference (Burnham, 1992). However despite such attention to diversity there has been relatively little attention paid (within this frame) to disability and dis/ableism

within the family therapy literature¹. In the therapeutic literature more generally exceptions to this include Hodge's (2013) article about ableism and its impeding of empathy in the practices of counsellors and psychotherapists. 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, 2009:5). Ableism is believing that nondisabled people are superior to disabled people. Reeve (2000) identifies what she described as psycho-emotional disablism in counselling practice where counsellors employ a predominantly medical model of disability that risks discounting alternative relational understandings. Both of these papers show therapists drawing upon culturally available discourses of dis/ability as the normative ideology as they construct their work and their worlds. Referring to the need for therapists to reflect on this normative ideology of disability, Smith (2004) draws the parallel with earlier concerns with 'whiteness' studies in family therapy work. This reflection calls for a focus on the construction of disability, as well as the construction of the normal, given that disability is often culturally seen as the absence of or deviation from the 'normal'. Disability is constructed in relation to the normal. That is disability is always understood as a problematic deviation from the normal, as an imperfection when judged against what is considered normative.

Critical Disability Studies

A key disability studies concept, developed by Oliver (1990), is the distinction between impairment and disability. This distinction is a core concept of what is known in the UK as the 'Social Model of Disability'. The social model constituted a challenge to medicalised and individualistic accounts of disability. Disability is conceptualised as the oppression of persons with impairments. Whilst the social model remains a foundational concept in disability studies it is not without critique. For example Tremain (2002) notes that impairment is also always socially mediated. A range of

¹ See Olkin (2001) for an approach to therapy informed by the social model of disability.

approaches termed Critical Disability Studies informs contemporary theorising about disability.

These include three related concepts: Normalcy (Davis, 2006), Disablism (Thomas, 2007) and Ableism (Campbell, 2009).

Normalcy (Davis, 2006) posits that the medical model of disability, where disability is considered to reside in the individual, is a core element of the othering of the disabled person. One aspect of this knowledge is about the measurement process by which norms for human beings are created as the focus of study and practice. Norms and the power of the medical epistemology is such that we are all subject to norms and we all struggle to achieve them. There is a corollary to the concept of the norm: that which is normal and natural and consequently also that which is unnatural and abnormal. As the categories of diversity increase and identity also becomes more fluid, normalcy scholarship focuses on the problem of the norms that create otherness rather than the identity category 'disability', itself a creation of a disabling society. Such a position might guide therapists to be sensitised to the understanding of unearned privileges of the non-disabled, the neurotypical or the learning abled.

Davis (2006) traces the historical development of 'diversity categories' and notes that categories of race, gender and sexuality, as they developed in the nineteenth century, were eugenic categories - they were initially all viewed as forms of disability, and deviations from the norm.

Disablism is described 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 wellbeing' (Thomas, 2007: 73). Disablism points to the oppression of disabled people alongside other forms of oppression such as racism, sexism and considers the oppression of disabled people as a cultural, socio-economic, psychological and relational phenomenon.

Disability is the always-present shadow of the fictional 'normal' body. It is a fiction for one is never really independent, bodies can become sick: and abilities are temporary. Ableism scholarship shifts its gaze from disabled people as a minority to understanding the processes by which some bodies become valued and centred and others devalued and marginalised. How does speech get valued over sign language, thinking over feeling, independence over interdependence?

This paper describes a Critical Discourse Analysis of family therapy literature. The idea for the paper took hold when the first author found the term ‘physically handicapped’ used in a contemporary family therapy textbook. The term ‘physically handicapped’ does not reflect contemporary usage and is considered to be anachronistic and insulting by disability activists and the disability studies community. This fuelled an interest in understanding how family and systemic therapists may be drawing on culturally available discourses of disability.

The Research Questions:

How is disability constructed in contemporary family therapy literature?

What are the discourses that family therapists draw upon when writing about their practices concerning impairment and disability?

Method

Four peer reviewed journals (*Journal of Family Therapy*, *American Journal of Family Therapy*, *Family Process* and *Journal of Marital and Family Therapy*) published during 2010 and 2011 were searched for texts relating to disability. This search resulted in a data corpus of 36 articles, with four articles where disability could be considered a central focus. The 36 papers were then read in detail. Critical Discourse Analysis (CDA) (Fairclough, 2001) guided the analysis. CDA “is critical in the sense that it aims to show non-obvious ways in which language is involved in social relations of power and domination, and in ideology. It is a resource which can be used in combination with others for researching change in contemporary social life” (Fairclough 2001:229). Discourses are understood as providing frames for what can be said, what can make sense and who may be warranted to say these things. References to disability were identified in the texts and these texts analysed. We sought to find out what discourses of disability were being drawn upon, how did these discourses position the various actors and what might the consequences of this positioning be?

Findings and Discussion

Whilst the construction of disability in these texts drew heavily on medical discourses of disability, there are also significant instances of alternative discourses that served to challenge the dominant medical conceptualisation. We use fragments of texts from some the articles to illustrate the discourses we identify. Whilst reading these findings it is worth reminding the reader that these are not to be read as critique of either family therapy or of the authors or papers we examine. Rather we show how the existing cultural discourses of disability have the potential to get incorporated into the practices of family therapy.

Social Discourses of Disability

Just as the profession of family therapy has examined its theorising and practices through the lenses of sexism and racism; there is some indication in the data we analysed that dis/ableism is being considered.

Writing about intellectual disabilities, Purdy (2012) noted the various discourses that might justify family therapy's poor engagement in the lives of people with intellectual disabilities in the UK. Except for the therapists and psychologists who work in services for people with intellectual disabilities, other mental health services where family therapists may be employed, risk excluding people with intellectual disabilities.

Extract 1

'...to exclude a person from mental health services or therapy on the basis of their disability alone is no more justified than to exclude a person because of their race or gender.' (Purdy, 2012, p422)

Purdy indicates how these discursive barriers can be overcome by paying attention to government policies about discrimination and exclusion and giving up the claim of skill deficits in working with intellectually disabled people. Such claims are based on a construction of people with learning disability as belonging to a separate category of humanity.

In the following extract disability is explicitly raised as an issue of diversity in a paper that focuses on disability and diversity training for students of family therapy:

Extract 2

'Disability issues are often an overlooked part of diversity training' Laszloffy & Habekost (2010, p 343).

The paper constructs disability as a diversity issue. It draws attention to the social barriers experienced by disabled people as a student of the course notes:

Extract 3

'At the end of the day, the whole society is set up for people who are able to walk' (Laszloffy & Habekost, 2010, p343).

Extract 4 is from a case study about family experiences of the aftermath of post-concussion syndrome (PCS) (Yeates, Luckie, de Beer & Khela, 2010, p188) demonstrates how family ecology and the social world are easily factored in the practices of family therapist.

Extract 4

'Family therapists have focused on family and wider social contexts of physical illness to develop detailed accounts of how systemic and narrative processes are central to the meaning and trajectories of common conditions, including neurological disability'.

Equally noteworthy in extract 4 is the avoidance of the language of the medical model of disability to refer to PCS.

The extract below (5) comes from an article we examine further when we consider medical model discourse of disability in the next section. Here we see the therapist (Karen) searching for an alternative to a medical framing of Adam's disability.

Extract 5

'Karen wondered whether coming to terms with Adam's disability and its meaning might be facilitated by a spiritual connection, particularly for Richard, given his Eastern Orthodox background. However, she placed this hypothesis on a back burner'. (Breunlin, Pinsof, Russell & Lebow, 2011, p306)

Extract 5 fits Roosen's (2009) advice to therapists to search for multiple narrative framings of disability. In addition to the medical discourse of disability, Roosen identifies the social model discourse (disabled people are oppressed); moral discourse (disabled people are chosen); humanistic discourse (disabled people are human beings); and Crip discourse (disability culture).

Haydon-Laurelut & Nunkoosing (2010) describe work with an intellectually disabled man with and the group home in which he lived. The paper cites the social model of disability (Oliver, 1990) and there is evidence of disability being viewed as a relational rather than individual issue – it exists in the spaces between people. The paper suggests that a further consequence of the individual model of disability is that if you see disability as inside the person, you may see problems the person 'has' as related to the person's impairment.

Extract 6

'In this conceptualization there is a change of focus from the perceived personal characteristics of a person with intellectual disabilities... and the dilemma of 'staff' about how and when to help, to the exploration of relationships and the search for new possibilities'.

(Haydon-Laurelut& Nunkoosing, 2010, p77)

This discourse requires therapists to work (use their power) to position the person with disabilities as someone who is an 'actor' in relation, rather than passive recipient of services to be managed or coped with.

We noted one instance where disability was referred to by its absence:

Extract 7

*'As a **nondisabled**, upper-middle class, heterosexual person, I (JC) have undoubtedly benefited from certain privileges setting me up for "success" in the social world, but as an Asian-American woman who immigrated to the United States at the age of 11, I have also*

endured the pain of being seen by others, and subsequently, coming to see myself, as “different.” (Markham & Chiu, 2011, p504)

In the above extract the ‘non-disabled’ is unmasked - the invisible norm troubled by the use of the term ‘non-disabled’ as a privilege. This exposes the contrast to the highly visible ‘disabled’. It is worth noting that this discourse is invoked here to contrast with the otherness of the immigrant. Non-disabled is named here as the unearned privilege analogous to whiteness in critical race studies.

Medical and Individual Discourses of Disability

Medical and Individual discourses of disability predominated in the data. Haydon-Laurelut & Nunkoosing (2010) for example, employ aspects of the individual medical model in their paper as well as drawing on the social model of disability. The title describes a man who 'has' Intellectual Disabilities and also an individual medical model definition of intellectual disabilities is drawn upon as follows:

Extract 8

‘Intellectual disability may be understood as a significant limitation in intellectual functioning as well as in adaptive behaviour that originated before the age of 18.’ (Haydon-Laurelut & Nunkoosing, 2010, p73)

This works by closing down other possible meanings of disability and positions the person from the outset as someone who differs from an unstated, and untroubled, normate level of intellectual functioning.

In extract 9 (Weingarten, K, 2010, p5) we find illness and disability juxtaposed as objects for comparison or for sharing certain undefined similarities.

Extract 9

*'Individuals who are hopeful do better at problem solving, at managing challenging situations, **even** in coping with illness and disability'*

The emphasis added in the above extract, is our own as the use of the term 'even' is weighty in terms of the work being done with this sentence. Illness and disability are juxtaposed here as objects that need to be coped with. Medical discourses construct disability as a tragedy and as a time of challenge when one needs to draw on personal resources of hopefulness. The medical discourse offers individual solutions to individual problems and individuals who possess a trait called 'hopefulness' will do better at coping with disability. Impairment may be conflated with problems in living and the associated distress as in extract 10:

Extract 10

'The emotional and behavioural distress associated with learning disabilities' (Purdy, 2011, p3).

Critical disability studies challenges the understanding that 'disabled people are their impairment: *'They are broken individuals. They lack development. They cannot do. They do not have abilities to lead an independent life'* (Goodley, 2011, p80). In the extracts above and elsewhere in these texts, disability is assumed to be synonymous with impairment.

Once disability is viewed as synonymous with impairment and located within the individual, disability may then be something that can be measured. Disability may for example denote a kind of collateral damage to persons caught up in other problems, for example something a person can

acquire from drinking too much (Ruff, McComb, Coker & Sprengle, 2010) as the result of mental illness Pernice- Duca (2010), or use of psychoactive medication (Morris & Stone, 2011). Disability is an attack upon the person².

Extract 11

'...adult head and neck cancer patients and their families, a clinical population thought to be particularly vulnerable to negative psychosocial sequelae both because of the social isolation attributable to the physical disfigurement and disabilities resulting from the surgical and radiological approaches used to treat these cancers, and because of often unresolved family conflicts secondary to smoking and alcohol two well-known etiologic factors associated with these cancers.' Steinglass, Ostroff & Steinglass (2011, p395)

Disability in the medical frame refers to a deficit in functioning. This may be both caused by other disabilities and also lead to further 'sequelae'. This term refers to abnormality following disease or injury. In extract 11 social isolation and stigmatisation are framed as sequelae following 'disfigurement and disabilities'. This medically framed account produces a disorder, a psychosocial disease that positions the person as a candidate for psychological treatments. In this short paragraph pathology is located in the person's biology, psychology and intimate family relationships. However alternative stories are possible. For example a critical frame might foreground the unacceptable discrimination or the violence of disablism (Goodley & Runswick-Cole, 2011) experienced by those who have non-normative appearances.

² This is a difficulty with people first language (Titchkosky, 2001). This language of persons 'with' or 'affected by' disabilities creates a split subject a person is invited to annex a part of themselves (Campbell, 2009). The issues are complex and contested. For example, the disabled peoples movement in the UK generally uses the term 'disabled people'. People First the self advocacy organisation run by and for people with intellectual disabilities prefers the term people with learning difficulties.

A further subject position of disabled people in the medical discourse is that of disabled person as either excluded or at least as excludable. Here one has recourse to the language of disability as personal tragedy where the person is described as: ‘...*suffering from a documented developmental disability*’ (Linares, Rhodes & Montalto, 2010, p532). One is offered the subject position of the person who suffers, who may be in need of benevolence, but who can legitimately be excluded from participating in family research. The disability of the participant is likely to contaminate the data and its generalizability. This too is exclusion, albeit different from the documented ‘social exclusion’ of disabled people. There is a long tradition of disabled peoples exclusion as ‘outliers’ in psychological research, which serves the purpose of maintaining normalcy. The concept of the ‘norm’ or what is typical and its relationship to the term ‘population’ is important here. Disability when described as a ‘population’ (Skerrett, 2010, p505) risks creating/sustaining the norms from which this population differs³. Populations are objects to measure rather than people and forms of life to be understood and in the measurement ‘*disability can be made into a thing*’ (Titchkosky, 2003, p56). Such measurements can facilitate the delineation of further populations based on our measurements of severity, longevity, causes and so on.

Extract 12

‘Finally, students often come to appreciate how within every disability a counterbalancing strength develops... each (disability) creates unique demands and stressors that require a different set of compensatory skills’. (Laszloffy & Habekost, 2010, pp343-344)

Extract 12 draws upon an individual discourse that conflates impairment and disability as individual deficit; albeit of a kind that might assist in the development of other abilities that compensate for the

³ Skerrett (2010) also quotes research showing that disability may be experienced as an opportunity for personal growth as well as a negative part of life.

individuals deficit. This draws upon the discourse of ‘overcoming’ disability where the disabled person develops compensatory skills and also achieves perhaps spiritual growth.

Extract 13

‘Richard’s growing ability to accept Adam’s disability and to take it as a growth opportunity for him involved a spiritual shift that permeated other aspects of his life.’

(Pinssof, Breunlin, Russell & Lebow, 2011, p324)

In extract 13 it is the disabled child’s father who grows.⁴ The growth appears to draw upon a tacit acceptance of an individual tragic framing of Adam’s disability. In addition we note in the above quote the discourse of ‘acceptance’. It is not clear precisely what is being accepted and who is asking for acceptance however it may well be that it is the loss of normalcy that needs to be accepted – the passing of the son from the valued category of non-disabled to its binary opposite, disabled.

Discoursing ‘acceptance’ of a disabled son as an ability also positions the child and his disability as a challenge to the father; here too we note the taken for granted notion that acceptance of a disabled son or daughter has to be worked at.

Extract 14

‘Karen hypothesized that Emily and Richard were both challenged (Mind Hypothesizing Metaframework) by Adam’s disability, particularly his difficulties attaching to them. Emily and Richard experienced Adam’s disability differently (Gender and Culture Hypothesizing Metaframeworks), but both were deeply disappointed by his failure to develop along the

⁴ See Stainton & Besser (1998) and Hastings (2005) for research on positive experiences of parents of disabled children.

normal pathways and timelines like his 11 year old sister, (Pinsof, Breunlin, Russell & Lebow, 2011, pp317-318).

In the above extract the various hypotheses concern intersectional influences on the parents' experiences of disability, presented here as their disappointment with Adam's atypical development. The discourse 'developmental pathways' indicates that there is a predetermined trajectory of development that the child journeys through and a developmental disability such as Asperger's Syndrome is discoursed as a gap between this developmental norm and the child's attachment to his parents. However there is no need to state or define what might be in this gap, such is the power of the ableist discourse to render this without need for justification.

Extract 15

'Both became depressed and mute about their deeper thoughts or feelings. Their marriage fragmented and the good things about it (friendship, sexuality, etc.) eroded. Meanwhile, Kate, the daughter, felt abandoned, frightened (Mind), and lost with her parents' depression and preoccupation with Adam' (Pinsof, Breunlin, Russell & Lebow, 2011, p318)

The individual tragedy discourse finds disability as a threat to normal, healthy, family life. In extract 15 the tragedy discourse finds Adam's disability a family tragedy. In the following extract we find the threat of disability appearing to be constructed through the discourses of systemic theory (drawing on von Bertalanffy (1968) and Minuchin (1974) and individual tragedy.

Extract 16

'...when a family member becomes ill and disabled, if subsystem boundaries are too rigid for other family members to figuratively put their arms around that family member, the family

will not be able to address the problems and challenges presented by that member's illness. When system boundaries are too rigid or diffuse for a particular problem, organizational constraints emerge.' (Breunlin, Pinsof, Russell & Lebow, 2011, p302)

The systems metaphor and tragedy discourse construct family therapy as going beyond individual models of psychological deficit to accomplish both individual and family deficiency. Family organisation may prevent the necessary response to a person who has a disability. This will be a result of pre-existing flaws in their organisation as a system. Such a family may require therapy to assist in its proper readjustment to a normal state. Hypothesising occurs in culture and the hypothesis in extract 17 may be read as reflecting the culture of ableism, informed as it is by the discourse of the disabled child who causes his or her parents to live their lives in a state of chronic sorrow (Ohlshanky, 1962).

Extract 17

'Karen hypothesized that Richard and Emily had never processed their grief and sadness about Adam's disability - the parts that had to do this specific processing were hidden by other angry parts that lashed out at each other and kept them from experiencing their own and the others' sadness and grief.' (Breunlin, Pinsof, Russell & Lebow, 2011, p304)

The discourse of chronic sorrow implies a loss of the 'perfect child' and grieving as if the child is dead. Of course this may well be a cultural story that the family has also adopted as well as one shared by the therapist. The chronic sorrow discourse however also serves to construct the 'normal' against which disability is produced. When a 'normal' child is born, parents do not have grief or sadness to 'process'. It is implicit that the parent's expectations and hopes will be met following the birth of a 'normal' child. The unstated Ableist ideal (Campbell, 2009) operates here to produce the othered 'disabled' child. There are alternative narratives to chronic sorrow lived by parents of

disabled children⁵. Incorporating these alternatives in the hypotheses of the family therapist has the potential to enrich its practices.

Conclusion

This paper sought to interrogate some contemporary family therapy literatures' construction of disability. The articles we examined drew predominantly upon medical-individual discourses of disability. There is also a significant understanding of dis/ableism. A consideration of the problems of dis/ableism has the potential to open up new meanings. Disability and impairment were predominantly synonymous in the data and this suggests there is an important opportunity for the field to engage in critical reflection concerning the intersections with disability and impairment.

In the data disabled people are primarily problematic for families; they are problems to be coped with. Earlier forms of systems theory may have contributed to this disablist ontology by framing disability as primarily a threat to the family system. This kind of theorising positions the family therapist as one who engages in a form of family rehabilitation. This stays very much within a pathological discourse of disability and considerations of dis/ableism may well offer richer understandings.

The social model of disability and its challenges to the medical/individual model of disability has been in existence since at least the early 1980's and our interpretation of the data suggests that critical reflection is required concerning the theory and practice of family therapy with disabled people. Our interpretation of the data found discourses of 'normalcy' such as 'normal' family life, 'normal' developmental pathways and 'normal' processing of information about the social world. Attending to the problems of normalcy has the potential to destabilise the dis/ableist status quo. In doing so family therapy makes common cause with goals the disability movement.

⁵ For examples of alternative narratives of parents bringing up disabled babies see, McLaughlin, Goodley, Clavering, & Fisher, 2008).

Contemporary family therapy would appear well placed to engage with the complexities of disabled family life and tell richer stories of family lives than those encountered in our data. Moreover, therapists and researchers may be better able to support disabled people if they have access to a wider range of stories of impairment and disability (Roosen, 2009). This is an understanding of therapeutic work that is congruent with the ethos systemic therapy (Lang & McAdam, 1995).

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