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CHAPTER 3

Developing the Social Relational in the Social Model of Disability: a theoretical agenda

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Introduction

The emergence of the social model of disability in 1970s Britain placed new theoretical tasks on the agenda. By reformulating disability as social, the disabled peoples' movement and its academic wing, disability studies, opened up a black box of complex questions about this additional societal form of oppression. Important advances have been made in tackling some of the questions posed, but a great deal remains to be unravelled. It might be said that the journey has only just begun.

This chapter attempts to assist those on this journey by reflecting upon the terrain travelled so far and by working towards an agenda for further theoretical work. No doubt other writers' theoretical agendas would take a contrasting shape, but the one presented here, though only a starting point, may be of assistance. Of course, an agenda for social policy research would look very different, prioritising the immediate and pressing policy-related needs of disabled people in every area of social life. But disability studies needs a theoretical as well as a policy-oriented agenda, to secure the foundations for empirically related

work.

At the core of the observations set out here is a conviction that the *social relational* kernel of the early UPIAS formulation of a social understanding of disability (UPIAS 1976) holds the key to unlocking both the questions and answers concerning the nature of disability - its ontology. It defined disability,

as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have [impairments] and thus excludes them from the mainstream of social activities (UPIAS 1976: 14)

This lifted disability free from its traditional association with matters biomedical and placed it on a new social terrain. The 'social model' of disability was born. Disability now resided in a nexus of social relationships connecting those socially identified as impaired and those deemed non-impaired or 'normal', relationships that worked to exclude and disadvantage the former while promoting the relative inclusion and privileging of the latter. The new challenge was to: i) describe this nexus of social relationships, that is, to make clear the manifestations of disability in the social world (in organisations, systems, policies, practices, ideologies and discourses), and ii) to explain it, by employing theoretical paradigms that generate ways of understanding what gives form to and sustains these relationships.

How far have we come?

Success in making the manifestations of disability apparent, or exposing disablism, in the social world is evident in the emergence of a research literature on the 'social barriers' faced by disabled people in arenas critical to material wellbeing and civil status: education,

employment, transport, housing, health and welfare services, recreation, media and cultural representation, legislation and so forth (see the journal *Disability and Society*; Barnes 1991; Zarb 1995). These barriers have been uncovered and documented, highlighting key features of the landscape of social exclusion. Less attention has been paid to barriers in more 'intimate' life domains in which disablism social relationships operate, for example, familial and sexual attachments as well as in areas of reproduction, parenting and childrearing. However, research excavating disablism in these areas has also begun (Shakespeare *et al.* 1996; Thomas 1997, 1998, 1999). This success in bringing to the light the manifestations of oppressive social relationships between those designated impaired and those who qualify as non-impaired has been powerfully significant for disabled people. Experiences of inequity and exclusion have been named as such, perhaps for the first time, and as a consequence there have been important, if limited, shifts towards greater equality for disabled people in social policy, legislation and cultural imagery (Oliver and Barnes 1998).

Less of a success story, in my view, is the theorisation of disability as a social relational phenomenon, since the 1970s. Headway has certainly been made in a number of contrasting directions, three of which are now briefly reviewed.

First, historically materialist minded writers and activists like Vik Finkelstein (1980) and Mike Oliver (1990) have sought to locate the cause of the exclusionary nexus of social relationships that structure disability in the core workings of the capitalist economy. In late eighteenth and early nineteenth century Britain, the imperatives of a system of generalised commodity production demanded that non-owners of the means of production sell their labour-power, to be harnessed in the service of a fast

moving and exhausting industrial labour process. Those who could not sell their labour-power on these terms faced exclusion from the opportunity to independently obtain the means of subsistence – the decisive arbiter of social standing and merit in modern society (Oliver 1990; Gleeson 1999). The rest is history: workhouses, institutionalised care, enforced dependency, ‘special’ education, ‘sheltered’ workshops, community care, supported employment, and so forth.

Second, feminist writers in disability studies have shown us that the social relationships that constitute disability articulate with those that constitute gender relations. This means that disabled women and disabled men are understood to occupy different, if sometimes overlapping, social spaces, and the theoretical task of explaining their social positioning is made more complex (Thomas 1999). However, simple formulae like ‘disabled women are doubly oppressed because patriarchy operates in conjunction with disablism’ have long since been dismissed by disabled feminist writers (Morris 1996). The task of examining the interplay of disability and gender became more challenging as feminist perspectives on the nature of gender relations themselves became fragmented and attuned to multiple ‘differences’ from the 1980s onwards, reflecting the arrival of anti-foundationalist epistemologies in the social sciences and humanities in the academy (Skeggs 1995). This feminist attention to social diversity has had a widespread impact, including in disability studies where dimensions of difference among disabled people, in addition to gender, are recognised as requiring theorisation: differences associate with ‘race’ and ethnicity, sexuality, age, impairment type, class, and so forth. While the identification of the social barriers faced by disabled people occupying these social locations of ‘difference’ has begun, the theorisation of the social relational foundations that feed their particular experiences of social exclusion or inclusion is in its

infancy.

Third, writers heavily influenced by postmodernist and poststructuralist thought have called into question traditional parameters in the theorisation of disability. From a deconstructionist perspective, to assert that disability resides in a nexus of social relationships connecting the impaired and the non-impaired is to buy into the Enlightenment fallacy that such social categories and dichotomies (impaired/non-impaired, normal/abnormal) are 'real' (Price and Shildrick 1998; Corker and French 1999; Corker and Shakespeare 2002). In this view, to suggest that there are pre-social biological differences marking off the 'impaired' from the 'normal' is to commit the error of essentialist thinking. This sits alongside other errors of an Enlightenment strain such as trying to find the 'root causes' of oppression and, in some cases, trying to bring about 'progressive' change. From these anti-essentialist perspectives, disability theory centres on the interrogation of cultural categories, discourses, language, and practices in which 'disability', 'impairment' and 'being normal' come into being through their social performance, and on the power that these categories have in constructing subjectivities and identities of self and other.

These, and related, theoretical innovations have certainly energised our thinking about disability, and have consolidated the legitimacy of the claim that disability is a social question. But we remain on the cusp of significant developments in the realm of disability theory. What follows is a discussion of four themes, or areas, in which the social theorising of disability is urgently required. A short chapter on such complex questions means that the approach taken here is necessarily broad brush, but, hopefully, this will not detract from the utility of drawing together some priority themes for a theoretical agenda. My own feminist materialist perspective informs the agenda

that emerges, but I try to suggest how linkages can be made with other epistemologies. Put another way, the argument presented here is in favour of developing the social relational ideas inherent in the UPIAS (1976) definition of disability, and thus in the social model of disability it inspired.

Theme 1: Disability in a global economy: towards a contemporary political economy of disability

In attempting to look for the causal mechanisms of disability in the core workings of the capitalist system of production and exchange, writers such as Finkelstein (1980), Oliver (1990) and Gleeson (1999) have followed a well-trodden path in Marxist historical materialism. The profound economic, political and cultural changes brought about by the transition from feudalism to capitalism in the West, and particularly from mercantile to industrial capitalism, offered fertile ground for thinking about the creation of classes of people, including 'the feeble-minded', 'cripples', 'in-valids', deemed redundant and dependent on the grounds of their incapacity to present themselves as wage labourers. The consolidation of capitalist social relations of industrial production in nineteenth century Britain was a transformative force that altered all remnants of pre-capitalist social relationships at the micro and macro scales. In the new nexus of social relationships, children and adults with physical or cognitive characteristics that made them sufficiently at variance from the socially defined norms of embodiment found themselves not just dependent but, often, logistically separated and outcast in the warehouses that were the sanatoria, the asylums and workhouses (Braddock and Parish 2001). This approach to explaining the root cause of the social exclusions that constitute disability has, in my view, tremendous potential. It is a *political economy of disability*, but one that requires considerable development.

The historical analysis itself requires verification in terms of empirical evidence: what did people with impairments 'do' in pre-capitalist and pre-industrial communities, what were their social roles and status? What proportion of people with impairments were employed in early industrial society? What proportion of people with impairments were institutionalised once industrial capitalism had taken hold? What were the particular experiences of girls and women with impairments, and how did this differ from the male experience? What difference did other markers of ascribed social identity (age, 'race', sexuality and class) and of impairment type make to disabled people's social positioning? These questions hint at the large theoretical and empirical agenda that begins to take shape when one embarks on an historical account of the political economy of disability.

A more imposing challenge, and one of greater significance to disabled people today, is to develop a contemporary political economy of disability. We read so much about our supposedly 'post-industrial' society, about the dominance of the consumerist imperative in today's world, including 'MacDonaldisation' (Ritzer 1995), about the rapidity of global cultural change, about our risk society and the informational age (Castells 1996; Bauman 1998; Beck 1999; Giddens 1999), that we can easily forget that the vast majority of the world's population remains impoverished. The global masses in the developing world scrape a living through subsistence agriculture, wage labour and petty commodity production (often in combination) (Greider 1997; Canterbury 2000; Gilpin 2000; Thomas 2001; Pilger 2002). This not to be forgotten truth about the predicament of billions of people in the transnational capitalist economy seems to me to set the agenda for a new political economy of disability. That is, the examination of the position that people occupy in the social relations of production and consumption in the globally skewed system of generalised commodity

production and agriculture that penetrates every corner of the globe continues to hold the key to unlocking the social relational dynamics that construct disability. This is the case whether disabled people are in or out of the labour market. Of course, in any societal or regional context, close attention has to be paid to the particularities of the economic, political, cultural and historical profiles of those social spaces. But the basic task remains the same: to locate the tap-roots of contemporary disablism in the imperatives of the system(s) of production and exchange that exist in any region, functioning as they do under the tutelage of the World Bank, the International Monetary Fund and the US Treasury. One valuable resource for this work is the small but growing number of studies and accounts of disability in non-Western and developing societies (Charlton 1998; Stone 1999; Ingstad 2001; Priestley 2001).

The process of economic polarisation is important here, both on a global and local scale. Almost everywhere, poverty has become more extensive and deeply entrenched as wealth and access to resources is further concentrated in the hands of a minority (Thomas 2001; Pilger 2002). In Britain, for example, the last three decades have seen a sharp increase in poverty and income inequality, associated with changes in the occupational structure (the shift from manufacturing to service industries) and in marriage patterns and family structures, and with regressive Conservative Government policies on taxation and welfare expenditure in the 1980s and early 1990s (Graham 2002). How have disabled people fared in all of this? What are the gains, if any, and what are the losses? Which disabled people have joined the ranks of workers in the service sector, on what terms, and which have fallen into deeper poverty? What difference has 'New Labour' in Government made? Answering such questions requires an examination of the complex nexus of socio-economic relationships in which

people with impairments are now located (Sapey 2000; Roulstone 2002). The rapid spread in the last quarter of the twentieth century of electronic and information technology is, of course, a key feature of the present socio-economic landscape in the world's economically developed societies, and has much wider implications than the narrowly economic for the quality of life of people with impairments (Roulstone 1998; Sapey 2000; Abberley, 2002). Many new questions are posed for the theoretical, policy and empirical research agendas in developing these aspects of the contemporary political economy of disability.

The kinds of issues reviewed above are of little direct interest to those working with postmodernist and poststructuralist epistemologies. These writers focus on the current global *cultural* landscape - whether this is seen as conjured up by, as instigating, or as just corresponding with, global economic change. Those far more expert than I on the questions posed about disability by the deployment of these perspectives will have to comment on the theoretical agenda that emerges in these connections (Corker and Shakespeare 2002).

Theme 2: The psycho-emotional dimensions of disability

Attention now turns from the macro level to the qualities that social relationships display on a micro scale. I have argued elsewhere (Thomas 1999) that our appreciation of the exclusions that constitute disability should include those that work along psychological and emotional pathways. The oppression that disabled people experience operates on the 'inside' as well as on the 'outside': it is about being made to feel of lesser value, worthless, unattractive, or disgusting as well it is about 'outside' matters such as being turned down for a job because one is 'disabled', not being able to get one's

wheelchair into a shop or onto a bus because of steps, or not being offered the chance of a mainstream education because one has 'special needs'.

What is of particular interest here are the impacts and effects of the social behaviours that are enacted between the 'impaired' and the 'non-impaired', for example in familial relationships, in interactions in communities, and in encounters with health, welfare and educational services. Who has the power, and how is it wielded? What are the decisions made, the words said, the meanings conveyed, in these networks of relationships? And what are the effects on disabled individuals' sense of self, self-esteem, and existential security? In my own research on disabled women's life experiences (Thomas 1998; 1999), including those associated with becoming pregnant and having a baby (Thomas 1997), the operation of disablism along psycho-emotional pathways is a crucial dimension of being disabled. Some writers have touched on these matters using the concept 'internalised oppression' (Reeve 2002). This form of disability shapes in profound ways what people can *be*, as well as affecting what they can *do* as a consequence.

This concern to bring the psycho-emotional dimensions of disability onto the agenda is a consequence of my feminist interest in the experiential, the personal or private, the emotional and the intimate - to make these legitimate social subjects worthy of sociological attention in disability studies, an interest shared with writers like Jenny Morris (1996). I have written at length about the mistaken tendency within disability studies to reject what is seen to be public and 'confessional' dabbling in such 'personal or private' matters because this, supposedly, diverts attention away from the 'really important' disabling social barriers 'out there'. Such diversion is also feared because it appears to open up opportunities for the traditional 'personal tragedy' perspective on disability to re-establish

its hold (Thomas 1999, 2001). My argument is that by relegating psycho-emotional consequences of living in a disabling world to the realms of 'private life' or 'the personal restrictions of impairment' (Oliver 1996: 48), key dimensions of *disability* are ignored. The manifestations of disability are thus mistaken for the psychological angst of 'personal troubles'.

The psycho-emotional dimensions of disability have yet to be theorised; I have merely drawn attention to them. Where can we find the tools and methods for a full theoretical engagement with the social interactions and embodied processes that are involved in this form of disability? At the very least we need to draw on what is helpful in the sociology of the emotions, social psychology, psychoanalysis, and the phenomenology of lived experience (Hevey 1992; Shakespeare 1997; Williams and Bendelow 1998; Williams 2001; Corker and Shakespeare 2002). That is, what is helpful in these disciplines and literatures needs to be put to work in the interests of disability studies. We also need to draw on the insights of cultural theorists who look at the wider discourses that circulate in the media, arts, science and other aspects of the cultural superstructure, since these incubate the meanings and messages about impairment and 'unacceptable difference' that inform the attitudes and behaviours of us all. Postmodernist and poststructuralist perspectives can play an important role here for at least two reasons. First, they show how the discourses that bring into being the categories 'disability' and 'impairment' can be critically deconstructed. Second, they remind us of the need to look at the mutually constitutive nature of meanings in social interactions (Price and Shildrick 2002): in talking about you as a disabled person I not only perform the act of constructing who you are, I am also performing the construction of myself as 'normal'.

Theme 3: Theorising difference

Disability studies, like feminism, queer studies and other arenas of thought directed towards a greater understanding of the social position of relatively excluded groups of people marked off, or self-identified, as possessing particular attributes and characteristics, soon ran into the need to confront questions of difference. The unifying category 'disabled people', while of utility as a rallying cry in political struggle, soon came to be seen as problematic under closer analytical scrutiny. Questions were raised, for example: What are the qualifying criteria of being 'disabled', or 'nondisabled' – where are the boundaries drawn? What makes deaf people and people with spinal injuries 'the same' in their cultural labelling as 'disabled people'? Why do people in the Deaf community choose not to call themselves disabled (Corker 1998)? In what ways are some people more impaired and disabled than others? Why are old people with impairments seen as 'just old' rather than as disabled (Priestley 2003)? For deconstructionists, these questions are principally about the meanings embedded in the categories and labels themselves, and about how these are socially constituted; for the more materialistically inclined they are about the relationship between categories of meaning and underlying realities.

Such questions have occupied many writers in disability studies in the last twenty years, and many dimensions of difference have been engaged with, either singly or in their intersection: gender, sexuality, 'race' and ethnicity, age and impairment type (see, for example, the journal *Disability and Society*; and note the absence of 'class' from this list, something yet to be addressed). The processes shaping identity and disavowal are also drawn to the foreground, as is the im/possibility of a disability identity politics (Shakespeare 1996, 1997; Wendell 1996).

The degree to which differences and identities are

understood to be socially constructed depends on the epistemological perspectives that are being brought to bear. As noted earlier, poststructuralist writers eschew the 'essentialist fallacy' of the pre-social fixity of social categories like 'disabled', 'women', or 'black', pointing instead to their ever-fluid and always-newly-created-in-cultural-practice character. In contrast, materialist or realist commentators look for what embeds differences in 'real' but changing socio-biological substances, while fully acknowledging that these are overlaid by social constructed categories of meaning – meanings that are formed in particular temporal and spatial contexts, and thus possess fluidity.

The further development of this area of theorising and research is essential if the potential of the social relational understanding of disability in the UPIAS (1976) formulation is to be unleashed. To suggest, as that formulation does, that disability resides in a nexus of social relationships connecting those socially identified as impaired and those deemed non-impaired or 'normal', is to invite questions about difference and sameness on all sides, such as those rehearsed above. It is also to invite questions about the intersection of dimensions of social oppression, for example: disability, age and gender. In my view, however, the postmodernist and poststructuralist pursuit of these matters, while insightful and of value in many ways, holds the dangers of falling into an all-consuming spiral of linguistic and discursive deconstruction. Such a spiral has little to offer those who want to obtain a theoretical grounding to support empirically and policy-oriented research and/or a disability praxis that holds out the possibility of making *real differences* in the lives of disabled people. But if that is a danger along a deconstructionist pathway, a danger for those informed by other theoretical perspectives is the down-playing of the significance of difference, both among

disabled people and between disabled and non-disabled people (Oliver 1996; Oliver and Barnes 1998). Many challenges lie ahead for disability studies in adequately theorising the complex threads of social commonality and divergence (Thomas 1999).

Fresh approaches to thinking through difference are much to be welcomed

- for example, Mark Priestley's engagement with disability over the life course (Priestley 1995, 2001, 2003). His operationalisation of a perspective that interrogates disability across the generations, paying attention to the dynamics of both social structure and agency over the life course, is a powerful way of engaging with difference, one that develops important conceptual insights for the theorisation of disability. More work of that ilk is required in disability studies.

Theme 4: Impairment and impairment effects

In my view, the argument that disability studies requires a theoretical engagement with impairment has been heard and widely accepted. One piece of evidence for this is the inclusion of a chapter on disability and the body, by Bill Hughes, in Barnes et al.'s recent edited collection, *Disability Studies Today* (2002). This development deserves much encouragement, not simply because it helps us to understand impairment *per se* in social terms, but because, in dialectical fashion, it can assist in deepening our understanding of disability. To unpack that claim, let us return once again to the UPIAS formulation:

disability is identified as: the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities (UPIAS 1976: 14).

Social modellist thinkers soon extended this definition to cover all impairments: physical, intellectual and sensory and, more recently, to mental illness (Barnes 1991; Barnes et al. 2002). The point here is that in this social relational proposition, disability and impairment are inextricably linked and interactive: *disability is social exclusion on the grounds of impairment*. Impairment does not cause disability, certainly not, but it is the raw material upon which disability works. It is the embodied socio-biological substance -socially marked as unacceptable bodily deviation - that mediates the social relationships in question. The particular character of the impairment plays a critical role in shaping the forms and degrees of disablism encountered (of course, impairments vary greatly in nature: physical, sensory, intellectual, cognitive, behavioural; visible or invisible; singular or multiple; stable or degenerative, and so forth). It follows that the theorisation of disability requires the theorisation of impairment, but in what directions?

There are many theoretical routes that can be taken. A poststructuralist deconstruction of the concept 'impairment' and of the 'impairment/disability' dichotomy has exercised some minds (Corker and French 1999; Corker and Shakespeare 2002). In contrast, materialistically oriented writers could usefully develop a political economy of impairment by building, for example, on the early work of Paul Abberley (1987). He considered the socioeconomic origins of impairment in industrial capitalist societies, enabling us to appreciate that much impairment is created through industrial processes and accidents, through pollution, through medical advance as well as blunder, and through wars and famines. In my view this is an important line of analysis which could gain much by drawing on the voluminous published research undertaken by social epidemiologists, medical sociologists and others on the social aetiology of health inequalities (Graham 2001, 2002). Making links, on our own terms,

between the disability studies agenda and health inequality scholarship is an important move that is yet to be made. This would throw important light on the generation and distribution of impairment, and hence of disability, and would underline the connection between socio-economic disadvantage, illness, impairment, and disability, over the life course. This is only one of many challenges facing those who want to develop a materialist ontology of impairment.

A theme that has attracted greater attention in disability studies is that of the rapid shifts in knowledge in the genetic and biological sciences, with its therapeutic and eugenic implications for medical practice (Shakespeare 1999; Shakespeare and Kerr 2002). Given the enormous significance of this 'brave new world' for disabled people, getting to grips with such developments must, surely, occupy a high ranking position in the theoretical agenda of those interested in both impairment and disability. This requires at least some engagement with the substance of the genetic, biological and medical sciences, as well as with the ideas of those who critique these sciences – as in the literature emanating from the sociology of science and technology (Varcoe et al. 1990; Law 1991; Franklin 1997). This is a daunting but necessary task. One problem, in my view, is that it is poststructuralist theoretical perspectives that occupy a hegemonic position in the contemporary critique of science. Materialist and realist approaches are sorely needed in this field.

I would suggest that theorising the socio-biological dynamics associated with different types of impairment should occupy a place on the disability studies agenda, something that writers in the learning difficulties field have drawn particular attention to (Goodley 2001). As indicated above, this assists in understanding the forms and degrees of disablism in operation in our society. In my own work (Thomas 1999), one feature of trying to think

through impairment differences and consequences has involved the introduction of the concept 'impairment effects'. It seemed to me that such a concept was required to acknowledge that impairments do have direct and restricting impacts on people's social lives – 'restricting' as judged against socially defined age-norms. Such restrictions are, of course, to be distinguished from the restrictions, exclusions and disadvantages that people with impairments experience *as a result of disability*. In any one life, impairment effects and disability interlock in unique and complex ways. However difficult it may be to separate impairment effects and disability effects in someone's life, it is necessary to make such an analytical distinction within disability studies, but taking care not to mistake the former for the latter.

The concept 'impairment effects' requires considerable theoretical development. I have a particular interest in taking this into the domain of 'chronic illness and disability', an area currently under-conceptualised and researched in disability studies. This would include the study of cancer and disability, something barely touched upon to date. Once again, other literatures can be helpful here, not least the work of medical sociologists (Barnes and Mercer 1996; Thomas 1999, 2002; Williams 2001). In whatever ways it is taken forward, I suggest that the concept 'impairment effects' does have a place on the theoretical agenda.

Conclusion: developing the social-relational in the social model of disability

This chapter took as its starting point the social relational kernel in the proposition that disability is social exclusion on the grounds of impairment. This means that disability involves a nexus of social relationships between those designated impaired and those designated non-impaired or normal, relationships that work to exclude and disadvantage the former while promoting the relative

inclusion and privileging of the latter. The theoretical challenge is to understand what gives form to and sustains these relationships, however and wherever they are manifest – in social structures, organisational practices, systems, policies, ideologies, discourses and inter-personal relationships.

Four themes have been identified to head-up a theoretical agenda in disability studies: the political economy of disability; the psycho-emotional dimensions of disability; theorising difference; and, theorising impairment and impairment effects. It has been shown that each theme contains many sub-themes and potential lines of analysis, but of course this brief chapter has only been able to hint at the richness of the theoretical questions that each theme embodies. Other writers would no doubt construct theoretical agendas of a different cast, their priorities being informed by perspectives other than the feminist materialist world-view that has shaped the one set out here. That is to be welcomed rather than lamented: disability studies is enriched by the dynamic exchange of ideas from a broad range of social scientific perspectives.

The attempt to craft a theoretical agenda in this chapter has not been done in the spirit of mere academic whimsy. On the contrary, I would suggest that disability studies has reached a point, certainly in the UK, where there is a pressing need to think strategically about the theoretical tasks that lie ahead – with the scope being global rather than local or regional. While it is perhaps too strong to suggest that this young discipline has lost some of its early vitality and radical edge, the time has come, in my view, for a re-energised engagement with the formulation of both theoretical and policy-related agendas. In saying this, it is taken as a given that the close liaison between disability studies and the disabled people's movement will continue to act as the necessary power-house and testing ground for action and ideas. In the final analysis,

theoretical agendas and contributions are only of value if they can inform a rights-oriented disability praxis.

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