Defining a Theoretical Agenda for Disability Studies
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- First let me say what a privilege it is have the opportunity to address you all at this conference. [Add personal reflections on conference].

- I want to share with you some of my thoughts on the future direction that disability studies might usefully take. The wealth of papers presented at this conference indicates that our discipline has indeed come along way in the last decade and more – we have witnessed here that there is a richness and sophistication of research and analysis in our UK and international community that should be much celebrated. But I want to look ahead and consider some pathways that, in my view, need to be taken if we are to develop our discipline and ensure that it is of service to the disabled people's movement.

- My concern here, then, is with the directions and pathways for theoretical work. My focus is on answers to the question: what might a theoretical agenda for disability studies look like?

- This is not, of course, to deny the importance of other agendas – and policy-related research agenda, for example. On the contrary, the policy agenda is of crucial importance. In the UK, it is essential to continue to map out in detail disabled people's losses and gains in independent living, employment, education, and in other arenas of life as our so-called 'New' Labour

government passes through its 7th year in office. But others will have to talk about that policy agenda. My interest here is in the theoretical underpinnings of all of our research and thinking, including policy-related research.

- However, before I can outline the top four themes in my vision for a theoretical agenda for disability studies, I want us first to spend some time thinking about the meaning of our core concept: <u>disability</u>. I've recently been writing a paper that has involved comparing the ways in which some UK writers in disability studies would answer the apparently simple question: what is disability? I've come to the conclusion that the meaning of this absolutely core concept is still unclear and variable. You would think that by now we would have got our act together on this one, that we all meant the same thing when we refer to 'disability' - but we do not.

- Let's be clear, I'm <u>not</u> talking now about our different ways of theorising the forces and processes that bring disability into being. Of course we vary hugely on such questions, depending on whether we are a materialist, a postmodernist, a phenomenologist or whatever - and differences in perspective on what brings disability into being and sustains it are much to be welcomed. Rather, I'm talking about our lack of clarity on our very starting point: on our understanding of what disability itself *is*.

- I would argue that if you investigate the meanings of the term disability in currency in disability studies today you will find, at root, two meanings in circulation:

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1. disability is restricted activity (caused by social barriers)
2. disability is a form of social oppression

- I want to spend a little bit of time examining these two meanings.

- Those who adhere to the <u>first position</u> – that disability is restricted activity – will almost invariably go on to say – in the very next breath - that disability is caused by social barriers, and that those barriers amount to social oppression or exclusion. So, at first sight, this position does not appear to differ very much from the second one: both end up by saying that disability *involves* social oppression. But when you strip away all the statements about what causes disability, this first position leaves you with a kernel, a starting point, <u>that disability is restricted activity</u>. Further, this kernel does not seem at all odd or problematic to people because it corresponds to a normative meaning of disability in our culture: that is – that disability is about not being able to do things, it is about restricted activity.

- Those who adhere to the <u>second position</u> – that disability is a form of social oppression – are in my view in a minority in disability studies – and I count myself among them. This is how I see the origins of this position: in the 1970s, in drawing up a manifesto for the disabled people's organisation UPIAS, Vik Finkelstein and Paul Hunt tried to completely change the meaning of the term disability. They argued that disability is not simply restricted activity in and of itself, but is in essence something else. Disability comes about as a result of those actions of the non-impaired majority in society that constrain the lives of people with impairment – their actions through social structures, organisations, professional practice, and at the level of interpersonal interaction. In this way, disability, or disablism, joins sexism, racism, and homophobia as a form of social oppression. Disability becomes a social relational category – that is, it is an effect and quality of

relationships of power and exclusion between groups of people in our society. In this view, the meaning of disability <u>does not</u> correspond to any normative ways of thinking about what disability is in our culture.

- Now, both of these positions claim the mantle of the social model of disability. Those who tried to redefine disability to mean a form of social oppression can quite rightly claim that their position lay the foundation, historically, upon which others - Mike Oliver to be precise - built the 'big idea' of the social model of disability. On the other hand, those who see disability as restricted activity - but (in the next breath) caused by social barriers – the first position - will argue that this expresses the essential features of the social model stance.

  But these are, in my view, quite different ways of understanding what disability is.

- Now, you may be thinking – Isn't she splitting hairs? Why does this matter? Don't these understandings of disability amount to the same thing? Don't both positions say that disability involves social oppression?

- Well, I'll give you one good reason why it does matter: In recent years, disability studies in the UK has become somewhat clogged up with what I think are fruitless and rather time wasting arguments about the relationship between impairment and disability. Some of you know what I am talking about – the many words that have been spilled and uttered in arguments either for or against the claim that impairment causes disability. These disagreements have turned into, or now take the form of, very heated arguments for or against the social model of disability itself – because the social model is

identified with the idea that disability is entirely caused by social barriers.

- So, for example, we read claims that the social model of disability should be abandoned because it mistakenly denies that impairment plays any role in causing disability. We are told to 'get real' – to acknowledge that impairment does cause some restrictions of activity and therefore does cause disability in some measure.

- Now, that last sentence says it all. If you think about it, these arguments about whether impairment does or does not cause disability only arise if one is using the term disability to mean restricted activity. My own response to the question: Does impairment cause restricted activity? is to say: Yes, of course it does! Any of us who live with impairment knows that it directly restricts our activity in significant ways. Does impairment therefore cause disability? Well, only if you define disability as restricted activity. If that is your position, then yes, impairment does cause disability.

- But that is not how I understand or use the term disability. If disability is understood in the second social relational sense – to mean a form of social oppression – the view that I favour - then the fact that impairment causes some restrictions of activity is really neither here nor there. This is because the term disability is now ring-fenced to comprise only those exclusionary restrictions that are visited upon people with impairments by the organisations, institutions and individual actions of the non-impaired. I say 'only' those types of restrictions – but of course those are the key restrictions that determine the quality of life of people with impairments: restrictions in jobs, housing, income, access, status, acceptance, education and so on and so forth.

- I've laboured these points about the meaning of disability because I think that disability studies needs to move on from the recent flawed, circular and tangled debates about what does or does not cause disability, and about whether the social model of disability should or should not be abandoned. Disability Studies needs to achieve clarity and agreement on what disability is – as our starting point.

- I'd like to see our discipline rediscover the importance of the social relational understanding of disability that the early UPIAS pioneers introduced – disability as a form of social oppression – and to make this the foundation, the underpinning, of our work. We need such a firm foundation if we are to think creatively and with a purpose about a theoretical agenda for the future of our discipline.

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- So, having made that plea, I can now turn to setting out one version of a theoretical agenda. Your own theoretical agenda for disability studies might well look very different, but here are my top four priority themes:

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> To develop a contemporary political economy of disability

> To understand the psycho-emotional dimensions of disability

> To theorise difference

> To theorise impairment and impairment effects

- I want to talk about each of these in turn, but only have time here to say a few words them.

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- First, <u>to develop a contemporary political economy of disability</u>.   SLIDE

  As a materialist, I place enormous importance on understanding disability as located in critical ways in the core workings of the capitalist system of production and exchange. Important work by Vik Finkelstein, Mike Oliver and Brendan Gleeson has enabled us to understand how, <u>historically</u>, disability emerged as both a modern social relational category and a harsh reality of life for thousands of people in the long transition from feudal to capitalist society. We know how by the 19th century in Britain this newly constructed, economically rooted, form of social oppression meant that children and adults with physical or cognitive characteristics that set them apart as different found themselves not just dependent but, often, logistically outcast in the warehouses that were the sanatoria, the asylums and the workhouses of the day.
  We now need to bring these kinds of analyses up to date.

  This same theoretical perspective needs to be applied to the contemporary global capitalist economy.

We read so much about our supposedly 'post-industrial' and consumerist society - MacDonaldisation, about the rapidity of global cultural change, about our 'risk society' and the 'informational age', that we can easily forget the basic reality that the vast majority of the world's population remains impoverished.

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The global masses in the developing world scrape a living through a combination of subsistence agriculture, wage labour and petty commodity production. This not to be forgotten truth about the predicament of millions of people in the transnational capitalist economy sets the agenda for a new political economy of disability. That is – the key to unlocking the social dynamics that construct disability is to examine the position that people with impairments occupy in the social relations of production and consumption in the globally skewed economic system that penetrates every corner of the globe.

Of course, in any societal or regional context, close attention has to be paid to the particular features of the economic, political, cultural and historical profiles in 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.

Economic polarisation should also occupy our thinking on a local scale. In Britain, the United States and other 'rich' countries, poverty has become more extensive and deeply entrenched as wealth and access to resources is further concentrated in the hands of a minority. In Britain, the last three decades have seen a sharp increase in poverty and income inequality

associated with changes in the occupational structure, changes in marriage patterns and family structures, and as a result of regressive Conservative Government policies on taxation and welfare expenditure in the 1980s and early 1990s. How have disabled people fared in all of this? Which disabled people have joined the ranks of workers, on what terms - and which have fallen into deeper poverty? Answering such questions requires an examination of the complex nexus of socio-economic relationships in which people with impairments are now located.

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. Many new questions are posed for the theoretical, policy and empirical research agendas.

Some of you here, I know, are working on pieces of this kind of jigsaw – whether your focus is on disability in the rich nations or in the developing world. But – and to mix my metaphors - the threads of such work need to be drawn together and built upon within disability studies – purposively woven together in the development of a contemporary political economy of disability.

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- SLIDE   Let me now turn to the second theme in my theoretical agenda: **to understand the psycho-emotional dimensions of disability**. This involves moving from the macro level – political economy - to the qualities that social relationships display on a micro scale.

- I have argued for some years now 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: being turned down for a job through prejudice, or not being able to get one's wheelchair onto a bus.

- What is of particular interest here are the impacts and effects of the social behaviours that are enacted daily between the 'non-impaired' and the 'impaired', for example within the family, in interactions on the street, and in personal encounters with health, welfare and educational professionals. In these interactions: who has the power, and how is it wielded? In these close networks of relationships: what are the decisions made, the words said, the meanings conveyed? And what are the effects on disabled individuals' sense of self, their self-esteem, and existential security?
- In my own research on disabled women's life experiences, including experiences of becoming pregnant and having a baby, the operation of disablism along these psycho-emotional pathways is a crucial dimension to being disabled. 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 and private, the emotional and the intimate - to make these legitimate social subjects worthy of serious attention in disability studies. This is an interest shared with writers like Jenny Morris and others.

- I have written at length about what I see as the mistaken tendency among some within disability studies **to reject** giving attention to these more 'personal or private' matters. This rejection is because such attention, supposedly, diverts us away from engaging with the 'really important' disabling social barriers 'out there', or because it appears to let the traditional 'personal tragedy' perspective on disability in by the back door.

- But my argument is that by relegating psycho-emotional consequences of living in a disabling world to the realms of the 'private' - or, as Mike Oliver had termed it to 'the personal restrictions of impairment' – we end up by ignoring key dimensions *of disability.* The manifestations of <u>disability</u> are being 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. For me, one of the really encouraging features of this conference is the significant number of papers that are explicitly addressing psycho-emotional aspects of disability – examining how this operates in a range of social contexts. I really welcome this.

- To develop theoretical work on this theme I think we need not to be afraid of drawing on <u>what is helpful</u> in other disciplines: for example, in the sociology of the emotions, in social psychology, in psychoanalysis, and in the phenomenology of lived experience. That is, what is helpful in these disciplines and literatures needs to be <u>put to work</u> 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 domains in the cultural superstructure. These discourses incubate the

meanings and messages about impairment and 'unacceptable difference' that inform the attitudes and behaviours of all. The postmodernists, poststructuralists, and cultural feminists among you play a crucial role here.

- So, let's get on with the job of developing our theoretical understanding of the psycho-emotional dimensions of disability.

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- SLIDE   Let's turn to the third theme in my theoretical agenda: **theorising difference**. This is a theme upon which much important theoretical work has already been done.

- Disability studies, like feminism before it, soon ran into the need to confront questions of difference. Particularly in the 1990s, the unifying category 'disabled people' came to be seen as problematic under closer analytical scrutiny. Questions were raised such as: What are the qualifying criteria of being 'disabled', or 'non-disabled'? Where are the boundaries drawn? What makes deaf people and people with spinal injuries 'the same' in their grouping together as 'disabled people'? How do dimensions of difference – disability, gender, race, sexuality, and so on, interact? In what ways are some people more impaired and disabled than others?

- For postmodernist thinkers, these questions are principally about the meanings embedded in the categories and labels themselves, and in how these are socially constituted. Poststructuralists warn of 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.

For the more materialistically inclined, questions of difference are about the relationship between categories of meaning and underlying realities. Materialist or realist commentators look for what embeds differences in 'real' but changing socio-biological substances, while fully acknowledging that these are overlaid by socially constructed categories of meaning.

- The further development of this theoretical theme is essential if we are to realise the potential of the social relational understanding of disability bequeathed to us by the UPIAS pioneers. To suggest that disability resides in a nexus of social relationships connecting those deemed impaired to those constructed as 'normal', is to invite questions about difference and sameness on all sides – about the disabled <u>and</u> the non-disabled. And it invites questions about the intersection of dimensions of social oppression: disability, gender, race, and sexuality – and let's not forget to add – social class and age.

- In pursuing this theoretical theme we must avoid two dangers: first the poststructuralist danger of falling into an all-consuming spiral of linguistic and discursive deconstruction of our differences; second the materialist danger of down-playing the significance of difference, both among disabled people and between disabled and non-disabled people.

- So, many challenges lie ahead for disability studies if it is to more adequately theorise the complex threads of social commonality and difference.

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- Finally, the forth theme in my theoretical agenda:
  SLIDE **theorising impairment and impairment effects.**

  I think the argument that disability studies requires a theoretical engagement with impairment has been heard and widely accepted. This is much to be encouraged, not simply because it helps us to understand impairment *per se* <u>in social terms</u>, but because, in a dialectical fashion, it can assist in deepening our understanding of disability.

  Please don't make the mistake of thinking that I want us to theorise impairment and impairment effects because 'these might play a role in causing disability'. As I said earlier, if you understand disability in social relational terms – as a form of social oppression – the fact that impairment causes some *restrictions of activity* is neither here nor there. Disability is about something else. This does not mean, however, that we can ignore impairment and its effects. On the contrary, it is very important that we theorise these in disability studies.

- Here are two reasons why this is important.

  <u>First</u>, in the social relational understanding of disability, 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.

- <u>Second</u>, the particular character of our impairments plays a critical role in shaping the forms and degrees of disablism that we encounter. And, of course, these vary greatly.

- What directions should this theorisation take?
  Many theoretical routes are open to us.

  For example: A poststructuralist deconstruction of the concept 'impairment' and of the 'impairment-disability' dichotomy has exercised some minds, and this is important work to take forward. The work of Mairian Scott-Hill (Corker) is important here.

  In contrast, writers of a materialist persuasion could usefully develop a political economy of impairment by building on the work of Paul Abberley. He has considered the socio-economic 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, and it could gain much by drawing on the now voluminous published research undertaken in other disciplines on the social aetiology of health inequalities. 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 light on the generation and distribution of impairment, and hence of disability. It 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 different line of work that has attracted greater attention in disability studies concerns the 'new genetics' and bio-ethics. This follows the rapid shifts in knowledge in the genetic and biological sciences, with its therapeutic and eugenic implications for medical practice. Tom Shakespeare's important research comes immediately to mind here.
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.

- Yet another direction involves theorising the socio-biological dynamics associated with different types of impairment, something that writers in the learning difficulties field have drawn particular attention to. This is essential if we are to understand the forms and degrees of disablism in operation in our society.

- In my own work, one feature of trying to think through impairment differences and consequences has involved the introduction of the concept 'impairment effects'. This concept requires considerable theoretical development. I have a particular interest in taking this into the domain of 'chronic illness', an area currently under-conceptualised and researched in disability studies. It seems to me that the concept impairment effects is required to acknowledge that impairments do have direct and restricting impacts on our lives. In any one life, impairment effects and disability interlock in unique and complex ways – ways that we have yet to fully understand.

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- To summarise and move to a close.

- I've argued that disability studies needs to achieve clarity and agreement on what disability is – as our starting point. I've stated that I'd like to see our discipline rediscover the importance of the social relational understanding of disability that the early UPIAS pioneers introduced – disability as a form of social oppression – and to make this the foundation, the underpinning, of our work.

  What I've told you about the top four themes that make up my theoretical agenda for disability studies is premised on this social relational understanding of what disability is.

- How would your theoretical agenda differ? Whatever our own agendas might consist of, the important point I want to finish on is that we need to be thinking creatively about where we are heading on this front. 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 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 close links between disability studies and the disabled peoples' movement is essential – the movement will continue to act as the necessary power-house and testing ground of ideas. In the final analysis, theoretical agendas and contributions are only of value if they can inform a rights-oriented disability praxis.   Thank-you.