Ostrich Politics: Exploring the place of social care in Disability Studies

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<picture 1 slide>

I am going to talk here about the reluctance of disability studies in very recent times to acknowledge, the central position of social care, 'welfare' and social work in the lives of disabled people in the UK. I will suggest that social care in particular has become a poor relation in the brave new world of the social model and direct payments but I will also suggest there are a number of reasons why it is important to continue to acknowledge the centrality of social care in disabled people's lives. In particular I note that the de-emphasis on social care or refusal to engage with the realities of social care and the part it plays in most disabled people's lives in the UK, leads to an unhelpful impasse where the 'solution' to the failures of social care is *coming to be seen* as abandonment or turning the back upon social work, social care and all things social service. This leads to a situation of 'ostrich politics' where disability studies appears to be moving away from the realities of life for ordinary disabled people. I will illustrate the reasoning behind this position with examples from a completed project undertaken with disabled refugees and asylum seekers. Social care research of this type must continue to influence policy makers and governments to ensure that the poorest and most oppressed disabled people obtain access to necessary social care services.

Background

Historically, in the UK Disability movement, authors acknowledged the central place that social care played within the lives of disabled people. Admittedly, this acknowledgement mainly took the form of intense criticism, which in itself formed the mandate for the development of the social model and social action (Finkelstein 1991). Social care, and in particular, rehabilitation services, came to be seen as outmoded and disability activists such as Finkelstein pointed to the ways in which such services were the 'care' part of the 'cure and care' approach (Finkelstein 1991.35). These services it was claimed were founded upon and in many ways perpetuated,

individual model thinking, encouraging the idea of 'social death' (ibid). These criticisms formed part of the change in perspective sweeping through community-based support in the mid-1980s and 1990s and within which disabled people mounted a series of challenges to the status quo. These challenges centred on the issue of professional power (Finkelstein 1991). Notably Mike Oliver wrote about notions of power exerted by 'experts' (professionals) and how the emergent 'community care' contained both implicit and explicit assumptions concerning disabled people's capacities to choose their destinies. Jenny Morris wrote in 1993 that although community care plans contained statements of commitment to enable people to live independent lives and although these were compatible with the independent living movements' assertion that disability is a civil rights issue, the effect was merely superficial because community care policy views disabled people as 'dependent people in need of care' (Morris 1993.38). These critiques of community care policy came at a time of great change in the social work, (later to become social care) field. Bringing us much more up to date then, Direct Payments are fashionable because they fulfil the role that social care services used to fill and for those disabled people who use them, appear to fulfil this role well.

<picture 2 Godzilla, the runaway Romford ostrich who broke out!>

However, only 6,486 disabled adults in England (physical, sensory impairments, learning difficulties and mental health totals) between the ages of 18 – 65 years are currently using direct payments (Department of Health 2002a). The reasons for this low take-up are unclear and although worrying and interesting as a topic, do not concern us centrally here. The question I want to ask is, what forms of support are all the other disabled people using? This is where social care services in some shape or form (as well as private and voluntary provision) have their major role. If we look at the Community Care Statistics 2002 (Referrals, Assessment and Packages of Care for Adults) (Department of Health 2002b) (2001-2002 England), Table P2f.1 of this document, 'Estimated number of clients receiving community-based services during the period by primary client type, components of service and age group' shows for total number of clients

receiving services aged 18-64 (having physical and sensory disability, learning disability, mental health, substance abuse, other vulnerable people (asylum seekers and welfare benefits), the figure is put at 402,000. For the sake of correct comparison, if we deduct 12,000 the government has included for 'substance misuse' and 20,000 for 'other vulnerable people' you are left with 370,000 people. If we deduct from this figure, the 6,486 we know are using Direct Payments, we are left with 363,514 people receiving some form of social care service. That is about 56 times the number using Direct Payments.

Now this seems to me to represent a mandate for action. It seems to me that this centrally concerns us here at this conference because we have to continue to engage with issues of the quality of social care provided to disabled people in the UK, we have to be at the forefront of lobbying for improvements and we had to undertake the social care research that provides the stimulus for those changes to occur. Why is social care coming to be seen as the poor relation in Disability Studies? As an example of this I point to the contents of Disability and Society journal – acknowledged as the major forum for discussion of issues in Disability Studies – between January 2001 and the latest issue March 2002, only 4 articles dealt specifically with social care and its provision to disabled people:

<slide 3: table + picture 1 again>

Disability & Society	Articles on social care	Number of Articles
March 2002	0	9
January 2002	1	5
December 2001	1	9
October 2001	0	8
August 2001	0	6
June 2001	1	7
May 2001	0	6
March 2001	1	7
January 2001	0	6
Total	4	63

Obviously attempting to 'resurrect' social care does not go down well with the folks who think all disabled people should be moving to direct payments, who say that direct payments are the way ahead because they are rooted in the social model and who point out that social care services will never be rooted in anything other than individual/medical model. I have a lot of empathy with these views and agree with most of them but holding them gives us another problem – or rather two problems:

<slide 4: questions and ostrich>

- What do we do in the meantime? Until the hallowed state of all disabled people being on Direct Payments is achieved, what form does social care service take?
- 2. What do we do if the number of disabled people using Direct Payments does not increase? Supposing that the figures actually represent 'saturation point' – the most that it is ever going to be?

These two problems directly throw up a third:

- 3. Had we better not find ways to improve the quality of social care services provided to disabled people, even if this proves to be 'just in case' both 1 and 2 continue to pertain? And this leads to a fourth question:
- 4. Is this not best done through debate at conferences such as this one and through the press, rather than trying to hope social care will just 'go away' like an embarrassing relation?My argument as you can probably imagine is that we have to engage with 3 and 4 now and in the future.

Disability studies has to keep a toe-hold within the social care field because social care research can be used as an instrument to effect improvements in disabled peoples' lives. It does this by influencing government policy and practice. I want to illustrate this point by showing you some findings from a recent study concerning groups of disabled people who experience extreme poverty and oppression – disabled refugees and asylum seekers. The law in relation these groups is complex and in the very recent past has become more so, as the government tightens its grip on refugee status in relation to moral panics fuelled by the British media. However, it is important to remember here that refugees have the same rights as British citizens (this is why the government guard it so closely). All asylum-seekers are, to some degree or other in a state of flux concerning the legal status and rights to remain in the UK.

<slide 5 invisibility and ostrich>

Invisibility of disabled status

Firstly, our research acknowledged that, in many respects disability is a non-issue for those in charge of making decisions concerning asylum-seekers and their rights to remain. All claimants are looked upon as 'asylum seekers' only. It was rather telling within the research that, at the time we began the study (1999), the Home Office could not tell us the number of disabled asylum seekers they had seen in the last year *because they did not have accurate figures on the numbers of asylum seekers at all.* This, rather conveniently, made it impossible to gauge the extent of impairment within the asylum seeking communities. Attempts to find references to disabled asylum seekers in policy documents such as: the government white paper *Fairer, Faster, Firmer: A Modern Approach to Immigration and Asylum*, the subsequent *Immigration and Asylum Act 1999* and both the consultation paper on the integration of recognised refugees in the UK (Home Office, 1999) and the white paper *Secure Borders, Safe Haven: Integration with Diversity in Modern Britain* (Home Office 2002) also proved fruitless. What is happening here then? All we know is that there is an official wall of silence concerning impairment within the asylum seeking communities.

Barriers to getting a community care assessment

<slide 6: the large gate, ostriches inside>

Local authority social service departments have a responsibility to '*carry out an assessment of care needs.. and ensure that care being given was what that person needed*' (Department of Health, 1998, p. 13). However, a series of legal challenges have meant that local authorities can claim that they are unable to provide the required services because of resource limitations

(Valios, 1997). Therefore, although an individual's service requirements are recognised, legally, they can continue to remain unmet. Although undergoing a Community Care Assessment (CCA) does not therefore mean that an individual will receive the support they need. Blackman (1998) argues that 'at present, social care assessments appear to offer the best approach to *identifying need*' (p. 193), even if support then has to be targeted at those most in need, leaving some people unsupported. Many local authorities make charges for services (Department of Health, 1998), which further confounds access in situations of insufficient financial resources. Between 1996 and 2000, concerns were expressed through the media about the expectations placed upon local authority social services departments to provide destitute asylum seekers with housing and subsistence under the National Assistance Act (1949) (Vaux, 1998; Travis 1999). This requirement was dissolved from April 2000 by the implementation of the Immigration and Asylum Act 1999 which formally ended entitlements to social security benefits for all new asylum seekers and transferred responsibility for destitute asylum seekers from local authorities to the National Asylum Support Service (NASS). NASS provides 'destitute' asylum seekers with accommodation on a 'no choice' basis and subsistence support (currently £36.54 per week, which equates to 70% of Income Support level benefit). The Act also instigated a policy of dispersal, with asylum seekers being sent to areas of the U.K that had not previously housed significant numbers of refugees and asylum seekers. Nevertheless, recent court cases (for example in Westminster) have confirmed that local authorities retain their obligation to undertake community care assessments of *disabled* asylum seeker's requirements for services. In other words, it is only on the grounds of disabled status that the asylum seeker can stake a claim to a community care assessment from social services. In practice, in our study, impairment frequently became invisibilised within the social care service sector, disabled people were passed from disability teams to asylum seeker teams once that status became known. This then made it unlikely that they would be viewed as eligible for community care assessments.

Why is it so important that people can gain access to community care assessments? It is because these assessments are a 'gateway' to so many other forms of personal assistance, particularly for disabled asylum seekers.

<How we did the research> <not covered in verbal paper>

Qualitative interviews were undertaken with 38 disabled refugees and asylum seekers living in England to investigate access to social and welfare services. The interviews were conducted by seven first language interviewers who recruited from Somali, Vietnamese, Sorani (Kurdish) and Tamil communities via media contacts, refugee community groups and by utilising snowballing. All but one of the interviewers had been through the asylum process. Each interviewer recruited adult (over 18 years) disabled refugees or asylum seekers from their own linguistic communities (see Table 1). Participants were eligible for inclusion if they identified as a disabled person and they had arrived in Britain as a refugee or asylum seeker. A total of 15 women and 23 men participated in interviews. The participants were adults of all ages (range 19-75). Twenty people had physical impairments, six people were deaf or partially deaf, three people had visual impairments, one person had mental health problems and eight people experienced multiple impairments.

Barriers to Health

In 1984 the government burned our house. Also in 1969 they burned our second house. When I came to {location] to do my exam they arrested me when they saw my identification. After that they put me in jail. Also they beat me and broke two of my teeth. I told them I am a Haemophilia patient; they did not listen to me. I stayed bleeding for three days in jail.... In 1995 after they saw my identification they broke my right knee. I showed my disability identification; still they broke my right knee. The government when they harassed me, put an electric shock in my brain.

This quote came from a young man in the study and demonstrates the harrowing nature of many of the accounts detailing incidents that were clearly deleterious to peoples' physical and mental health. These barriers to health are illustrated by the following model:

<slide 7: model 1>

The experience of undergoing severe hardships as a result of civil unrest affected at least half the participants and, a core group of a quarter of the participants had similarly intense life-threatening experiences such as this person. Some had been exposed to chemicals, others were shot during times of war:

I became disabled when I was in my country. The car I was travelling in was attacked by gangs, who shot and the bullet hit me. My disability is called paralysis (no feeling or movement in lower part of body).

Of the 38 participants, nine gave graphic accounts of having been tortured whilst in prison. One described his experience as follows:

In 1984 I was in prison and due to the torture, one of my kidneys stopped working which was removed in an operation. {I was freed after two months then} I was arrested again with 3 of my friends. After 40 days they executed (shot with bullets) all my three friends and they gave me 7 years imprisonment during which I was beaten, tortured and thrown about. One time they blindfolded me, pulled and threw me to the wall. My head was injured. They took me to hospital to sew my injuries. After that I was withdrawn, depressed, fainting and my conditions got worse.

[The terrorists] hit me. Once they took me to their camp and gave me an electric shock. Also the [government] army took me and when I told them I am deaf they did not believe me. Also they said I was lying and hit me.

This was not unusual: several other participants encountered this reaction to declarations of impairment, especially deafness. These accounts of extreme situations in which the participants were in fear for their lives, add a further dimension to the experiences of oppression

Barriers to Safety

Every participant had undergone experiences that posed severe barriers to their personal safety, in order to gain access to this country. Two participants experienced **total** theft of property, (a regime taking everything that they owned) leaving them exposed to the elements and destitute. Several participants were psychologically intimidated and receiving death threats from political oppositional members, prior to their decision to flee their country of origin. They gave graphic accounts of desperate escapes from persecution in their countries of origin. As the next model shows, they faced persecution in three main areas; political persecution, religious persecution and disability persecution.

<Slide 7: Model 2: barriers to safety>

The barriers faced by the participants were political persecution, religious persecution and disability persecution (being actively discriminated against on grounds of impairment), destruction of home (often sequential and total), total theft of property (losing all material possessions, including clothes) and the receipt of death threats.

Following periods of political persecution, several participants described undergoing an exodus in small boats and nearly losing their lives on several occasions:

I didn't like the [ruling political regime] so I ran away. I escaped by boat with my daughter and relatives (nieces and nephews). We were in the ocean for 11 days and eventually picked up by a British ship.

In 1987, the government bombed my house in [location]. Also in 1994, they bombed my [new] house. I lost my one eye...I came alone...my family are in [location]. After I left.. I do not know their details. Because of that I am mentally upset. I do not know what is happening with my family.

Several of the participants described religious persecution:

(Interviewer) Could you tell me about your situation? What led to your leaving there?(Participant) Because of the killing. The army is killing the population there.(Interviewer) What problems did you face in particular? Was it just because you were a civilian?

(Participant) No. They were killing [religious group] there. It was religious [reasons].

Other participants described disability persecution, which contributed to their decision to flee to the U.K.:

I returned to [country of origin] in 1996 and stayed there until 2001. The situation was no better than when I left in 1989 and there were so many abuses of human rights. The regime was extremely tyrannical and I was personally discriminated against because of my disability. I was unable to find work and no college would offer me the opportunity to study because of my disability. I did my best to survive but it was difficult. Normally you obtain a work permit to find decent work in [country of origin] but the usual practice is to bribe the police to give you a work permit but I do not have the amount of money. I could not get decent work in [country of origin] and I ended up working on the street. I shined people's shoes on the street but I was often mugged and robbed of the little money that I earned. I was unable to chase after these muggers because I walk with a limp and cannot run. Despite of my condition, police have never helped me to catch the people who robbed me nor offered any help.

These barriers to safety experienced in the country of origin, continued to exert influence once the participants arrived in the U.K. Few could forget the extreme life situations they had experienced and the majority experience severe anxiety concerning relatives who had not escaped.

Barriers to Social Services

Having arrived in the U.K all the disabled asylum seekers then experienced barriers to accessing social services. These were comprised of three main types of barrier; information requirements, linguistic requirements and forced moves. We have already noted the legal position of entitlement to a community care assessment on grounds of 'disability'. In practice, securing the right to such an assessment is very difficult as demonstrated here.

<Slide 8: Model 3 here>

In relation to information requirements, we received consistently the same the response to a question on whether the participant had gained access to social services:

I do not ask for any services, I would like to, but I don't know what to request or how to initiate a request. I do not know who the service providing agencies are. I'm disabled and sitting at home.

(Interviewer) Do you get any help from a social worker?
(Participant) No
(Interviewer) Why don't you ask?
(Participant) I don't know who shall I ask?
(Interviewer) Do you know if you have a social services assessment?
(Participant) I don't know about this and how to apply for it.

The participants did not have access to information concerning what services and benefits might be available and therefore, had no way of asking professionals at these offices about them and initiating discussion about whether they were entitled to apply for them.

Moving on to inattention to linguistic requirements, the following similar problem was noted:

I want to express my illness but I cannot speak the language [English]. I do not know what to do. I think ...people... try their best but it is unfortunate that I do not speak the language.

Inattention to linguistic requirements has been noted in research with British minority ethnic families with disabled children (Ahmad 2000). Ahmed (2000) noted that provision of accessible information formats is a necessary precursor to successful establishment of service provision.

The policy of 'forced moves' that applies to asylum seekers under the NASS operated dispersal scheme, causes disabled applicants considerable problems, particularly in relation to necessary adaptations to property, due to the temporary nature of stays:

(Interviewer) What about other aids such as rails on stairs?

(Participant) We have asked for that but the property was rented from [a landlord] and he didn't like any modifications to his property.

Mrs. X is a strong woman, she is trying to find out what is wrong with the system and how she can get support. She doesn't trust the system after the bad experience she faced from the social services and the disease she has is incurable, but she tries to do her best. She needs support and counselling... She is staying in 3 bed rooms with her 5 children and husband. The situation is overcrowded.

Barriers to the Benefit System

Barriers were also experienced to the benefits system, even for those participants who had managed to surmount the linguistic and information barriers described previously. Many eligible people missed out on benefits, sometimes for decades due to a lack of knowledge of entitlements and of how to negotiate the benefits system. One gentleman had been part of an official refugee programme, but he was not told about Disability Living Allowance. As a result, he missed out on 22 years of disability-related benefits.

<slide 9: Model 4 here>

Model 4 summarises the barriers to the benefits system. These comprised two main types of barrier; official disagreements over status and inflexibility of the benefit system. Several participants experienced severe problems negotiating the social security benefits system and faced a confusing situation in which various officials disputed the extent of disablement:

<The> Doctor gave me <a>medical certificate; I received Invalidity Benefit for 12 months. After 12 months I was examined by the benefits doctor. I got 13 points. I needed 15 points in order to receive Invalidity Benefit. I was told to go to the job centre to sign on. Job centre said I cannot work I have to get Invalidity Benefit. The benefit department said I did not have enough points to receive Invalidity Benefit, I have to sign on at unemployment centre.

The system of Emergency Accommodation (under which asylum seekers were entitled to only board and lodging) was found to be operating a 'one size fits all' policy which caused considerable difficulties. The first language interviewer recorded the following example of the operation of this policy:

Male asylum seeker aged 25 who has mobility impairment and also has problems with his chest and back. He has been in the UK two months and lives on the first floor in a shared room in Emergency Accommodation. The people he arrived with have been dispersed to [a northern city] he is awaiting a Community Care Assessment (CCA)...He has to rely on other people bringing his food / drinks to the room and is only occasionally able to obtain cigarette stubs off other Asylum Seekers. He wants to go to [another city] where he has friends. The man had a hard time understanding the bureaucracy around the NASS (National Asylum Support Service) application form and CCA and did not understand why a doctor could not just confirm he is disabled...He is too scared to move to more suitable accommodation in case the people there do not want to [assist him].

The NASS system was similarly inflexible. At the time of fieldwork (1999-2002) NASS was operating the detested voucher system, in which the participants were given vouchers rather than

money. This caused multiple problems for the since the vouchers could only be exchanged at specific shops, some of which were a considerable distance from accommodation.

Barriers to social contact

On arrival in this country disabled asylum seekers require access to services of all types; housing, immigration assistance, education and training and sometimes independent living skills training in order to establish their position and secure their futures in the U.K.

<slide 10: Model 5 here>

Model 5 shows the barriers to social contact experienced. These were forced unemployment (being disallowed from taking paid work), lack of knowledge about disability organisations, lack of interpretation (a necessity to gain access to most forms of social contact), inaccessible buildings and forced dependency on family, friends and strangers (usually in the same accommodation). Severe social isolation was experienced. At the time of the fieldwork, asylum seekers were debarred from paid work ('forced unemployment') and yet many of the participants wished to work or take up training and educational opportunities.

(Participant) I would like to work and study, but my disabilities prevent me from that, that's why I spend most of my time at home...I suffer from the loss of memory that I why I cannot remember many things about last week...I am not happy because I cannot come and go as I wish and I am not able to work.

Only one participant reported having contact with a British disability organisation¹, which further limited opportunities for peer support and possible exposure to a campaigning stance based upon welfare rights. The vast majority of the participants found that they could not participate in these organisations usually due to linguistic barriers:

(Interviewer) Have you joined any organisations relating to your illness?

(Participant) No, it is for English speaking persons. I do not speak the language, so no.

This finding has resonances with the work of Ali et al. (2002. 248) who reached a similar conclusion in relation to work with Pakistani and Bangladeshi parents of disabled children. Failure to attend to linguistic requirements has also been found to restrict choice and to limit access to the right to challenge service provision decisions (Shah 1999).

Inaccessible buildings prevented participants' participation in English language courses and computer training, further limiting employment aspirations. Other barriers to social contact were noted in descriptions given of 'forced dependency' on family and friends:

(Interviewer) Do you have anyone to help you with personal care, shopping, housework or anything else this week? (Participant 1) Yes I have my cousin and a friend who comes around every other day and helps me with things.

(Participant 2) Money, in my case it is not enough for food, believe me I eat only once a day with my nephew's help who comes once a day to prepare food for me and spends every day one to two hours helping me with washing, laundry and other things.

The participants were forced to rely upon very intermittent sources of assistance and to rely intensely upon (typically) one source of support, demonstrating severely restricted access to social contact.

Conclusion to Section

The participants as I have demonstrated experienced barriers to health, safety, social services, the benefit system and social contact. Arguably, many of these barriers also continue to affect British disabled people who are not refugees and asylum seekers (c.f. Harris and Bamford 2001). However, the crucial difference is that the participants are far more likely to be confronting all of these barriers simultaneously.

The experiences of oppression and persecution undergone in the country of origin (on grounds of religion, politics and disability) was frequently compounded by the considerable barriers to accessing the basic necessities of life; food, shelter and warmth. Unsurprisingly, satisfaction of these necessities becomes the main priority, eclipsing often pressing requirements related to impairments. The picture that emerges is dire - of poverty, inadequate and unadapted housing and failure to render accessible both the social service and benefits system.

Conclusion <slide 11: laughing ostrich>

Disability studies has a history of engaging with social care. In many respects, the omissions and failures in social care appear to have been key factors in the original innovation of the discipline. In very recent times however, it has become unfashionable to talk about social care. However, a great many disabled people in the UK continue to use social care services and, it appears likely, that even within the brave new world of Direct Payments, this situation will continue to pertain. Examination of the 'extreme case scenario' of disabled refugees and asylum seekers, demonstrates the need for the continuation of the kinds of rights based action that was so evident in the 1980s and 1990s and in which many gains were made by the British disabled peoples' movement.

Whilst social care services remain so important within the lives of disabled people in this country, particularly for the pivotal role they play in the lives of multiply-oppressed people such as disabled asylum seekers, we have a duty to continually seek to influence and improve them.

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Model 3: Barriers to Social Service Provision







Model 5: Barriers to Social Contact

