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## Abstract

In this article I argue that an ethnographic approach has a contribution to make to the analysis of disability and development. Anthropologists document the experiences of disabled people whilst also critiquing the current operational structures and relationships that marginalise the rights of disabled people. The secondary argument states, if disability is to become a central part of all development agendas then disabled people must be made visible. Once greater visibility has been achieved it will be harder for development practitioners to ignore the specific needs of disabled people. A further benefit of using ethnographic techniques emerges through the analysis of how non-governmental organisations understand disability issues. Ethnographic research can both raise the profile of disability rights whilst also pointing out the short comings of current development practice.

## Comments

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# Challenging international development's response to disability in rural India: A case for more ethnographic research

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**Abstract**

In this article I argue that an ethnographic approach has a contribution to make to the analysis of disability and development. Anthropologists document the experiences of disabled people whilst also critiquing the current operational structures and relationships that marginalise the rights of disabled people. The secondary argument states, if disability is to become a central part of all development agendas then disabled people must be made visible. Once greater visibility has been achieved it will be harder for development practitioners to ignore the specific needs of disabled people. A further benefit of using ethnographic techniques emerges through the analysis of how non-governmental organisations understand disability issues. Ethnographic research can both raise the profile of disability rights whilst also pointing out the short comings of current development practice.

**Introduction**

The voices of disabled people are often absent from international development agendas or at best occupy a small sub group attached to a larger programme of development initiatives. Although non-governmental organisations (ngos) such as Action on Disability and Development focus specifically on disability issues, these organisations are relatively few within the wider international network of ngos. The network of UK based organisations represented by the British Overseas Non-Governmental Organisations for Development (BOND) consists of three hundred members. Only twenty seven are listed by BOND as funding specific projects on disability issues.[1] Fewer than ten of these organisations exclusively focus on disability. Scholars researching disability and development argue that disability should be central to the project planning of all ngos (Miles 1996). In this article I argue that in order for this to happen 'disability' must be made more visible to the international donor community. One way of doing this is through the documentation and promotion of the lived experiences of those who find themselves disadvantaged because of physical impairment. In this venture ethnographic research must apply a multi-layered critical perspective. Anthropologists should record case studies of people living with impairments across the developing world, but should also critically evaluate the relationships between donor agencies and those designated by them to receive resources. This critical analysis needs to ask questions about the ethics of how NGOs use images of disability and how resources are allocated.

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[1] The following link takes you to a list of BOND members that fund at least one project focusing specifically on disability issues.
http://www.bond.org.uk/database/activities/default.asp?strRequest=searchresults&Location=&Sector=119&Beneficiary=&Approach=&submit1=search

A further tier to this analysis should question the over reliance on the medical model of disability. When resources are allocated projects look to fund medical solutions to impairments rather than attempt to understand the often complex web of factors that render a person disabled.

Through a case study of one Indian family, three members of which are visually impaired, I highlight that a lack of direct and emphatic communication on the part of a donor ngo. This results in a simplistic and inaccurate representation of disability in rural India. In this case a lack of communication does not stop the ngo from taking photographs for the purposes of raising money. This visual prominence fails to translate into efforts to get to 'know' this family and understand how they live. The photographs are used to depict extreme hopelessness characterised by poverty and a stigmatising impairment. Furthermore the money raised through the constructed relationship between impairment and extreme hopelessness does not reach this family. The ngo justifies its lack of a specific disability agenda because it believes the physical needs of this family are met through other projects, namely, food programmes and general medical services. This medical approach to disability removes the need for the ngo to engage directly with this family. Instead of entering into a dialogue through which a more accurate picture of daily life is presented the ngo believes it already understands their needs. This case study highlights the assumed knowledge on disability of some ngos that seems to remove their need to communicate with those living with a disability. It also supports Beresford's (1996) argument that an automatic link between poverty and disability is made. In this case the ngo believes that in easing the physical affects of poverty they will also relieve the

impact of visual impairment. The ngo's distant diagnosis of the problems facing this family over simplifies the impact of disability on their lives. The lived experiences of this family are contradictory and impossible to understand without empathic, face to face dialogue. My case study shows that the immediate community offers daily support to the family. However this support has not removed deep-rooted prejudices about the nature and cause of disability. Ethnographic research enables these complex responses and attitudes towards physical impairment to emerge and it is from such insight that development practice should be based.

**The marginalisation of disability within development practice**

In this article I support a rights-based social model of disability. This defines disability as the loss or limitation of opportunities to take part in the everyday life of a community on an equal level with others due to physical and social barriers. I use Barnes's (1991) definition of the term *impairment*, namely a functional limitation within the individual caused by physical, mental or sensory impairment. My view expressed throughout this article (and shared by many for example; Oliver 2002, Barnes 2004, Corker 1999, Davis 2006) is that impairment need not lead to exclusion and inequality if inclusive development policies are implemented. I argue that at present this view is not shaping development policy on disability. The relatively few interventions directed at disability resourced by general rather than specialist development agencies stress the need for medical as opposed to societal solutions (Dhungana 2006, Miles 1996, dos Santos-Zingale and McColl 2006).

Masset and White (2004) and Yeo and Moore (2003) state that development agencies have systematically ignored disability, for they rarely include it as a separate issue on their agendas. I argue that little will really improve without development agencies commissioning more research that deconstructs the causes and impacts of disability in the developing world. This research needs to do two things; document the experiences of people living with impairments and map what action on disability is being taken evaluating the effectiveness of projects to identify good practice.

BOND's disability rights group (DDG) was commission in 1999 by the UK Department for International Development to conduct a mapping exercise recording the work ngos were doing specifically on disability. The research paints a picture of sketchy provision for disability within the wider BOND network.  In this paper Miles (1999) concludes that the development community must think more carefully about how to respond to disability issues in policy agendas. The paper recommends that tool kits should be put together by Bond's DDG to offer ngos practical help in responding to disability issues. Further suggestions are made such as the creation of a website containing up to date data on disability issues in the developing world. A timeline is given for the expected completion of this work. At the time of writing this article no link to this completed work was present on the BOND website. This suggests a significant delay in publishing the tool kits and creating the website. Furthermore, although a useful paper, the commissioned work is dated 1999 and no other evaluation document has since been posted. Again this suggests that the BOND DDG has been unable to move the agenda forward. Development agencies seem to be uncertain as to how disability as a

social construct should be responded to in practice. This is apparent in the hazy definitions of disability given by some international aid agencies.

**Confused definition of Disability**

A confused definition of disability makes it difficult for development agencies to launch coherent policies. The contemporary sociological understanding of disability as a social construct is supported by most development agencies. Both the United Nations (UN) and World Health Organisation (WHO) seem unsure as to how to practically translate a social perspective on disability. Brown (1999) highlights the UN's commitment to a social approach to disability, but also stresses that 'rehabilitation' and 'prevention' shape the UN's practical response. These terms are medically defined in terms of repairing or preventing damage to the body. The social aspect of life is only included in so far as the disabled person must be rehabilitated back into their community. The following classification of disability is used by WHO:

It acknowledges that every human being can experience a decrement in health and thereby experience some degree of disability. Disability is not something that only happens to a minority of humanity. The ICF thus 'mainstreams' the experience of disability and recognises it as a universal human experience. By shifting the focus from cause to impact it places all health conditions on an equal footing allowing them to be compared using a common metric - the ruler of health and disability. Furthermore ICF takes into account the social aspects of disability and does not see disability only as 'medical' or 'biological' dysfunction. By including Contextual Factors, in which environmental factors are listed, ICF allows to record the impact of the

environment on the person's functioning. (http://www.who.int/classifications/icf/en/ accessed 26/06/2007)

This definition primarily responds to disability through medical interventions. This is indicated by the relationship between illness and disability. When disability is viewed in terms of a bodily weakness the solution becomes a cure in the form of a medical intervention (Turner 1991). Although WHO acknowledges a social dimension to disability the emphasis on a body 'functioning' points to physical restraints rather than a complex intersection of social, cultural and religious beliefs. This reinforces a concept of physical normality that positions all other subjects as marginal. Nether definitions incorporate Barne's distinction between impairment and disability. This lack of a divide between physical restrictions and the social construction of a marginal identity causes confusion when it comes to devising practical interventions. The definitions conflate impairment and disability which makes it impossible to determine how the social dimension should be understood or responded to.  WHO and the UN represent hugely influential global development institutions which undoubtedly influence the practice of ngos. It is therefore not surprising that research claims that ngos utilise medical intervention to rectify the perceived 'damage' of the disabled body (Coleridge 1993). Ironically failure to address the deep rooted social, religious and cultural causes of disability further marginalises those with physical impairments, not least because the individual is treated passively through medical procedures.

**Gap between theory and practice**

This lack of a clear definition of disability exposes a significant gap between theory and practice. Research into disability has for a long time argued that a social constructionalist perspective enables analysis into complex processes of marginalisation that are the root causes of disability. This link between exclusion and social, religious and cultural processes has shaped practice within gender and development for some time (Visvanthan 1997, De Waal 2006, Harcourt 2006). Scholars have demonstrated the necessity for social relations to be viewed through gender in order to highlight how some men and women find themselves in positions of inequality. Equally disability allows for the same vital and critical analysis into factors that inhibit a person's autonomy.

One solution to the current imbalance between theory and practice within disability and development is the repositioning of disability as a central perspective through which social relations are viewed. Miles (1999) states that disability should be mainstreamed alongside gender. Gender has become an important dimension of project planning. Projects from the outset should consider not just the impact of gender relations on peoples' access to rights but also how impairments may prevent a person from interacting in their community as a full, active, independent member. Disability should be employed as an analytical tool in much the same way as gender is applied as a way of examining inequalities in social relations. Disability, as with gender, is a conceptual frame that identifies instances when a person finds themselves marginalised on the basis of a perceived physical impairment.

More ethnographic case studies recording the daily experiences of disabled people could help to highlight how important disability is as an analytical perspective. These case studies should pay particular attention to recording the self-perceptions and hopes for the future given by disabled people. If this is done it is likely that the projects desired by disabled people will be different from the interventions currently funded by ngos. For example, Dos Santos-Zingale and McColl (2006) show in their qualitative research into the approach of ngos to disability in war torn Sierra Leone that a western medical approach is taken that assumes the development practitioners 'know' what those with impairments need. The researchers of this article interviewed a number of people affected by the work of the ngos. They all expressed a desire for alternative approaches to responding to their needs. Most did not want medical solutions to rectify their perceived impairments or rehabilitation to integrate them back into their old lives. But rather wanted to be supported in setting up a sustainable community of people who shared their experiences of disability. The ngo had no knowledge of these views because they had not consulted community members as to their visions for the future (for similar case studies see Dhungana 2006 and Miles 1996). Lewis (2004) states that in order for women with disabilities to access micro finance ngos must acknowledge the extent of their experiences of disability. She goes on to argue that this can only be done if development agencies make disability a mainstream focus in the planning stages of all projects.

**The misuse of disability**

Ethnographic techniques can not only unravel processes of disability, but should also be used to expose instances when false images of disability have been constructed. A critical evaluation of the ways ngos interface with disability can highlight instances when they perpetuate relations of dependence adding to a person's disability. For example, the lack of knowledge into disability and its absence on development agendas has not prevented some ngos from using images of disabled bodies in their campaign literature. The use of such images for fund raising efforts provides further evidence that real people living with impairments are silenced by the overriding discourses on development practice.[2] Disabled people find themselves the focus in fund raising activities but are later marginalised when it comes to resource allocation. By using images of a disabled body in fund raising efforts the suggestion is made that the disabled person lives in a desperate state. While the link between poverty and disability is affirmed in my case study, without the inclusion of lived experiences of disability individuals are silenced, rendered powerless by development. Through an increase in data on disability the visibility and audibility of 'real' accounts of disability may prompt more direct and urgent donor responses.

Beresford (1996) points out that an analysis of disability based solely on poverty is both inaccurate and misleading. Disabled people are often presented as specimens of truly oppressed victims of backward societies in need of salvation. De Groot (1991: 115) makes a similar argument in relation

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[2] For examples see the following links
http://www.oxfam.org.uk/what_we_do/issues/gender/links/0798disability.htm?searchterm=disability, http://www.cafod.org.uk/about_cafod/what_we_do/health_and_disability

to women. She describes how women in this discourse are understood to be 'exotic specimens, as oppressed victims, as sex objects or as the most ignorant and backward members of "backward" societies'. Women are portrayed as a weak 'Other' contrasted against the strong liberated women of the West. Similarly I argue that a 'disabled body' is compared by the ngo in my case study to a constructed image of a 'normal' body (Smith and Hutchison 2004). In the context of development this 'normal body' is characterised not just by its physical appearance but also by its relationship with western modernity. Disabled people in the developing world are therefore rendered 'backward' both by the perceived inadequacy of their physical bodies and their inferior positioning in relation to western modernity. Although it is true that disabled people are among the poorest in the developing world (Kauppinen 1995), the constant use of extreme images of impairment and poverty homogenises disabled people into a single category of 'underdeveloped' reinforcing this association between disability and a state of backwardness.

In my case study there is a lack of even an attempt to dialogue with people with disabilities in rural Rajasthan. This lack of communication and the resulting stereotypes are hugely disempowering. Without direct communication those living with impairments are unable to speak for themselves and thus denied this basic human right. Ethnographic data on disability may help to improve communication through better knowledge and greater awareness between development practitioners and people living with impairments. This could lead to more active engagement with disability issues within development agencies and governments. In my research I consider

why there is not an attempt by the ngo representatives to listen to Neela's experiences of living in rural Rajasthan with a visual impairment. I conclude that prior assumptions have been made about what her life entails. Beresford states: 'There has been a tendency to isolate and lump people together indiscriminately as poor, without examining the different causes of their social and economic exclusion, and to stereotype them as dangerous or dependent. The effect has been to obscure both people's differences and their shared oppressions.' (1996: 554–5) Confused definitions prevent the emergence of coherent practical responses to disability as a socially constructed process. The labels 'poor' and 'disabled' are highly stigmatising and an unhelpful basis for action. To be poor and disabled is not just about a low standard of material comfort and subsistence; it is also about a denial of rights. In addition, such labels fail to allow individual disabled people to articulate their different experiences of both poverty and impairment.

**Case Study**

I will now present an example of the kind of application of ethnographic techniques that can simultaneously achieve a more complex understanding of processes of disability and the lived experiences of those affected by physical impairment. At the same time provide a critique of the inadequate approach to disability currently pursued by some ngos. The family are from a village in Jaipur District, Rajasthan. I visited this family in January 2001 with a western donor agency. The experience of visiting the family provoked many feelings and reactions in me. These experiences have remained with me and motivate

my argument for improved communication between all those involved in development relationships.

I spent six months living in the same area of Rajasthan as this family. I visited them on a few occasions and learnt of their progress through the local Gandhian NGO. It was clear that, there are restrictions in terms of the life opportunities open to this mother and her daughters. Although their daily subsistence is ensured by the help and support of the local community this brings a relationship of dependency and should not be mistaken for a collective commitment towards inclusively.

Neela is a blind forty-three year-old mother of two daughters. Both daughters Prem who is twenty and Shobila who is twenty-four are also blind. The father's name is Krishnam; he is fifty-five and is the only sighted member of the family. This family is from a low caste known as Kumhar, which translates as potters. It is traditional for Kumhar families to earn their living making and selling clay pots, which are used for carrying and storing water and for agricultural purposes such as grain storage. Krishnam is unable to work because he must look after his wife and daughters. Because this family is so poor they have no access to technology and life is hard. Cooking is done over a fire, which means that wood has to be collected. The process of collecting, laying and lighting a fire is virtually impossible without sight. Collecting and carrying water from the village well is also complicated when you have no sight. Neela, Prem and Shobila cannot go out unguided.

I first visited this family in January 2001; it was a fleeting trip and I was with a group of representatives from a UK donor agency. It was a strange and uncomfortable experience. We visited the family in the pitch dark, for their

home had no light, mostly because of the cost of electricity. Suddenly flashes started going off from cameras. I caught glimpses of Neela, Prem and Shobila in the split seconds as the flashes went, but obviously they could not see me. The lack of reciprocity in this encounter is evident since no attempts were made by any of the party to describe themselves to Neela and her daughters. Instead the objective of the meeting seemed to be to capture this family on camera. The flashes able to expose, reveal what could not be seen in the darkness of the night. I later saw the photos of that night and felt uneasy. The camera had been pointed straight at their eyes; and the eyes captured in this shot clearly belonged to someone with a severe visual impairment. The pictures were then used on a display board to promote the work of the NGO. This family was used to depict disadvantage and extreme poverty. The message came through loud and clear this family needs our help.

Although Krishnam, Neela, Prem and Shobila did need material resources, responding to their disability requires a more sophisticated understanding of the various levels of discrimination they experience. A homogenous link between poverty and disability cannot do this and leads outsiders to assume that if material resources are in place, and the community is willing to ensure that Neela and her family receive what they need, the disabling affects of their impairments are dealt with. I asked them on another visit how they coped with everyday life. Krishnam described how family friends came each day with food and helped with household chores. Whilst this does highlight a level of physical 'support' it also indicates a long-term relationship

of dependency which must be experienced by Neela and her daughters as acutely disempowering.[3]

Among Krishnam's relatives, only his younger brother and his wife came to offer support. Krishnam's family was poor and not seen as a good match. Neela's family was keen to marry her to someone who would look after her. However, Krishnam was the only man 'willing to take her on', for other wealthier families thought that Neela would be too great a financial and physical drain. The difficulty Neela experienced in getting married highlights her social exclusion. Harris-White (1999) documents the difficulties disabled people in Tamil Nadu face in getting married and argues that these experiences point to an unequal access to rites of passage. Despite this level of exclusion, families belonging to the same caste have supported Neela and her daughters, and they maintained this support throughout long spells of heavy drought. This sense of responsibility that their community expressed towards them is perhaps linked to notions of caste identity. Borooah and Iyer (2005), Sharma (2002), Munda (2000) and Zene (2002) explore notions of collective caste identity and the sense of solidarity that is often forged between those of a low caste who feel themselves excluded from full participation in wider Indian society. The act of helping those positioned as less fortunate affirms collective identity and allows individuals to fulfil their dharma or duty (Knott 1998). Neela and her daughters are disempowered by their positioning as those in need of help. Furthermore if helping them

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[3] I accept that many of the views I express represent my own interpretations of Neela's experiences. Although I had many conversations with her she was reluctant to criticise her community as she relied heavily on their daily support. She did acknowledge the problems she had finding a husband and the impact her impairment had on the perception of her as a mother and a wife.

represents a way in which a community member can fulfil their dharma how might Neela fulfil her religious duty as a Hindu?

The donor NGO did not appreciate what it was like for Neela and her daughters to live with a visual impairment. The photographer called an end to the meeting as soon as he had the image that provided evidence of extreme poverty and suffering. The NGO made no attempt to find out the specific needs of the family, but merely used the image to reinforce a category of 'underdeveloped'. If effective strategies to ease the marginalisation of this family were to be implemented, they would have to be founded on an understanding of what support already existed and an appreciation of what kind of life Neela and her daughters would like to lead. Such information can only be gathered through open and empathetic dialogue.

A further problematic area emerges, this ngo does not fund any specific projects aimed at disability nor do they make any effort to ensure the needs of disabled people are met through their current projects. Therefore the ngo assumes that the needs of this family can be understood through their poverty rather than disability. Poverty has impacted on Neela's life. Water, food and medical care are essentials. However, in addition to poverty Neela and her daughters experience a further layer of exclusion. They cannot access these resources without physical support. As already mentioned, Neela and her daughters cannot draw water from the well or cook without the assistance of a sighted person.  Neela, Prem and Shobila are excluded from acquiring any skills that might make them employable. No adjustments are made to the limited educational provision available to the villagers. The ngo therefore imagines a static existence for this family, one in which their basic needs are

met but little else. It is also likely that Prem and Shobila, just as Neela did, will find it hard to marry and have families. Without efforts to change underlying religious, cultural and social attitudes towards disability, women who are perceived as unlikely to make a full contribute to a family lineage will be excluded from all rites of passage beyond birth until death.

Ethnographic literature on gender and social marginalisation in rural India (Gold and Raheja 1994, Purkayastha, Subramaniam, Desai and Bose 2003) suggests that Neela must have contradictory relationships with her community. Although she is helped through daily life, something that in itself is intensely disempowering, cultural and religious attitudes towards a woman who is thought to be unable to care for her family are harsh. A woman who fails (for whatever reason) to fulfil the dictates of the 'perfect' wife and mother is denied the status of a 'proper' Hindu woman (Leslie 1991). The role of women as the bearers of sons, nurturers and homemakers are normalised and deeply ingrained in the fabric of social relations. If you do not conform you are positioned on the periphery of that community, denied full membership and dislocated from the constructed status of a 'real Hindu woman' (Kakar 1979). Neela's status as a low caste, disabled mother of two daughters must be viewed negatively by those around her. These views may not be articulated directly to her but she must know they are held by all those who surround her. The opportunistic actions of the ngo photographer failed to capture this complex web of material poverty and social, cultural exclusion with its undoubted disempowering consequences.

This case study represents my attempt to gain an understanding of how others live and experience their specific impairments. While Yeo and

Moore's (2003) article leaves us in no doubt that societal factors marginalise disabled people in the developing world, this case study suggests that more ethnographic research is needed to document the contradictory responses. Here a community offers physical support whilst maintaining the oppressive set of social, religious and cultural values responsible for the exclusion of Neela and her daughters.

**Conclusion : ethnography as a basis for better communication**

Although a rights-based approach is needed to address the lack of resources given to disabled people in many developing societies, the mechanism through which these rights are to be delivered also needs to be examined more closely. At present the aid industry has not adopted a methodology that is reflexive enough to allow for the experiences and voices of disabled people to be heard. Until a more effective model is formulated and adopted it is unlikely that a social model of disability will ever be successfully implemented in the developing world.

To return to my main argument that ethnographic techniques should be utilised to increase the audibility and visibility of disability. Once the complex experiences of those living with impairments are brought to the central attention of all development practitioners a more responsive approach can be attempted. Better communication between development researchers and practitioners will feed improved knowledge which in turn should raise awareness of the specific experiences of people living with disability in the developing world. However in order for communication to occur a space for dialogue is needed.

Although disabled people living in the developing world need money, this money must be channelled through a dialogue that wishes to hear and respond to their specific experiences of marginalisation. In other words, if the social model of disability is to work effectively in the developing world it must be founded on a shift in how development agencies view the concept of disability. The biggest barrier to the implementation of a rights-based social model of disability is that, at present, power is exercised through money, and those who want donor aid must conform to the dominant rationality of the 'giving' institution (Hulme and Edwards 1997). According to Edwards and Hulme (1992) and Hulme and Edwards (1997), NGOs insist on certain conditions (which larger donor agencies have often set) that determine the specific nature of the projects implemented. Although images of disabled people may be used to encourage donors to give, once in receipt of this money disability is once again sidelined from the central development agenda. Those that hold the money and therefore power to set the development agenda often fail to view disability and gender together as sites for the most acute marginalisation. It is now well documented that the power of donor money serves often to block dialogue through which projects can be constructed in partnership with local communities. Individuals within target communities are therefore treated as passive subjects and are denied the agency to shape their own futures. This imposed subjectivity contradicts the stated objectives of development practice because it serves to limit rather than increase human freedom. Ethnography as a set of research techniques applies a critical perspective to its focus of study. Ethnographers should therefore use their methodology to expose the relations of power that impact

and shape experiences of disability. In doing so the gap between theory and

practice may begin to be filled and hopes raised for the practical

implementation of a rights-based model of disability.

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