# The Culture Concept:
# Anthropology, disability studies and intellectual disability

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## Abstract

A small number of anthropologists have been studying the social and cultural significance of disabilities for many years, dating from Ruth Benedict's 1934 study of the diverse ways in which epilepsy was perceived and treated in different cultures. This interest in disabilities, however, still remains relatively marginalised within the broader discipline of anthropology. Interestingly, the first major long-term anthropological study of disabilities involved research by Robert Edgerton into the social status and stigma associated with being labelled intellectually disabled in the United States of America. This paper will explore the history of anthropological studies of disabilities, focusing in particular on the study of intellectual disability. As part of this overview, I shall tease out some of the insights that have been gained through anthropological studies of intellectual disability in different cultures. However, anthropological interpretations of intellectual disability are limited if they focus solely on cultural meanings and social structures, significant though these are to the experience and understanding of intellectual disability. An analysis of the symbolic and social significance of such people's actions and behaviours is also fundamental. Such research broadens our understanding of the lives of people with intellectual disabilities, maintaining both a sense of the social and cultural context within which such people exist, as well as exploring the ways in which they interact and make meaning out of the particular circumstances of their lives. Accounts that incorporate both these aspects of

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intellectually disabled people's lives subsequently force us to question some of the assumptions that are bound up in the social model of disability.

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One of the first anthropological studies of "disability" was undertaken by the well-known North American anthropologist, Ruth Benedict. In her paper, "Anthropology and the Abnormal", published in the *Journal of General Psychiatry* in 1934, Benedict argued that rather than dealing with questions of why abnormalities occurred or how they could be treated, the whole notion of abnormality as a cultural phenomenon should instead be put under scrutiny.[1] Through a comparative analysis of American Indian and Siberian cultural attitudes towards epilepsy, Benedict observed that many of these cultures valued the trance states that occur with epileptic seizures, associating them with the authoritative and honoured role of spiritual mediums. In contrast, Benedict argued that Western cultures perceive epilepsy as "blots upon family escutcheon and as evidences of dreaded disease" (Benedict 1934: 61-2). Whereas the latter are branded "abnormal and reprehensible", the former interpretation of epilepsy makes it "an essential attribute of ideal man" (Benedict 1934: 72). As a consequence of these observations Benedict concluded that both normality and abnormality are culturally and morally defined, whereby normality "is primarily a term for the socially elaborated segment of [the chosen range of] human behaviour in any culture [while] abnormality [is] a term for the segment that that particular civilisation does not use" (Benedict 1934: 73). In other words, according to Benedict, the perception, judgement and treatment of supposedly "abnormal" conditions such as epilepsy are culturally relative and based upon different values and interpretations of both human behaviour and social roles.

Despite its obvious relevance to further cross-cultural and ethnographic research into a whole range of conditions that are labelled "abnormal" or "disabled" in Western cultures, Benedict's cultural analysis of epilepsy had little if any impact on the study of anthropology for over thirty years. The only other analysis of disabilities from an anthropological perspective during the intervening period was undertaken by Jane and Lucien Hanks. In their 1948 paper, "The Physically Handicapped in Certain Non-Occidental Societies", Hanks and Hanks sought to determine the social factors that influenced the status of persons with disabilities in Asian, traditional North American,

[1] Throughout this paper I shall use the terminology that was used by the person whose work I am discussing.

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Pacific and African cultures (Armstrong & Fitzgerald 1996: 253). Like Benedict, their methodological approach involved what has been termed "armchair anthropology"; the tendency to seek some sort of general cultural interpretation through a comparative analysis of a range of ethnographic material provided by other fieldworkers. Although such comparative accounts provide important insights into the diversity of cultural attitudes, practices and values associated with various "disabilities", the piecing together of ad-hoc references from a diverse and often incompatible range of sources does not allow for a truly in-depth analysis of what it means to be "disabled" within a specific culture. Nor do such accounts incorporate the full meaning of culture as an anthropological concept.

The concept of culture is a central feature of the anthropological enterprise. Like other disciplines, anthropology has a diverse range of approaches and sub-disciplines, from economic and environmental anthropology, through to psychoanalytic, symbolic and linguistic anthropology. While each of these approaches to the study of society ultimately focuses on different aspects of what it means to be a social and cultural being, the emphasis on culture as a significant and to some extent determining feature of social existence has become increasingly central to anthropological research. Influenced primarily by the early North American anthropology of Franz Boas and his students, Ruth Benedict and Margaret Mead, "culture", as both an analytical and descriptive concept, has gone through various permutations, to the extent that there is still healthy and vigorous debate between anthropologists about what "culture" actually means.

In the eighteenth century, culture signified that realm of society dealing with the high arts, with painting, literature and sculpture. While this is still a commonplace interpretation of the term, culture has also come to mean anything associated with the customs, manners and tastes of a particular class or society. However, in anthropological terms, culture has taken on far more specific meanings. The classic mid-twentieth century North American anthropological definition of culture drew upon this broad interpretation of culture as the customs and values of a society, but extended it to include the beliefs, ideas, practices, objects and instruments associated with that specific culture (Armstrong & Fitzgerald 1996; Kasnitz & Shuttleworth 1999: 3; Kuper 1999). This

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functional and descriptive interpretation of culture was challenged, however, by symbolic, semiotic and structural interpretations which emphasised the "patterns of meaning" embedded in symbolic forms and practices. In such interpretations, the aim of the anthropologist is to "render meaningful a way of life that is seemingly unintelligible", exposing, through the "thick description" of ethnographic fieldwork, the underlying logic and significance of different cultural practices and behaviours (Kasnitz & Shuttleworth 1999: 3; Geertz 1993a, 1993b). Criticism of the monolithic and static nature of such an interpretation of culture has, more recently, led anthropologists to incorporate issues of power, social structure, history and change into their concept of culture. As such, culture has also come to include the dynamic nature of negotiated meanings, embedded as they so often are in relations of power. In phenomenologically inclined interpretations it has also come to incorporate somatic, sensory and biological features of humanness (Kasnitz & Shuttleworth 1999; Jackson 1996). Consequently, culture is now interpreted as not just something that makes us who we are; it is also something that we create as human beings. Like meaning itself, culture is symbolic, structured and purposeful and is constantly open to negotiation and change (Austin-Broos 1987; Carrithers 1992; Geertz 1993a; Kuper 1999; Parsons 1970; Sahlins 1976).

This anthropological concept of culture therefore makes it a significant analytical tool for understanding the diverse range of cultural meanings and practices associated with disabilities. It emphasises the significance of disability as a culturally produced and negotiated construct. It highlights the different ways in which cultures understand what it means to be disabled within particular cosmological realms that interpret and define specific notions of humanness and personhood (Armstrong & Fitzgerald 1996; Ingstad & Whyte 1995; Jenkins 1993, 1998). As an analytical concept, culture also allows us to explore how individuals and cultures engage across the difference of disability in order to make meaningful the experience of being in the world as disabled (Gleason 1989, 1994; Klotz 2001). The potential insights and contributions of anthropologists to the field of disability studies could therefore have the effect of broadening the parameters of discussion and analysis both within anthropology and disability studies. Rather than constantly reproducing the medical versus social model dichotomy, which has so dominated disability studies, anthropological research has the capacity to offer new

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insights into what it means to be disabled within specific cultures, into how these meanings are differently negotiated, and how the experience of being disabled is a complex product of social, cultural and biological factors.

However, despite its obvious potential, the impact of anthropological research on disability studies continues to remain relatively negligible. While a small number of anthropologists have pursued an interest in disabilities since the late 1960s, very few have contributed a uniquely anthropological perspective to the broader study of disability.[2] Some anthropologists have focused on particular types of disability, such as deafness, blindness or intellectual impairment, and sought to discover the social and cultural factors that influence the experience of being disabled in such ways (Angrosino 1998; Becker 1980; Deshen 1992; Edgerton 1967; Gleason 1989). Others have attempted cross-cultural analyses and used these to reflect on the diversity of cultural interpretations of disability and the problems associated with universalising Western biomedical practices (Edgerton 1970; Ingstad & Whyte 1995; Jenkins 1998; Manion & Bersani 1987; Nuttall 1998). Others still have reflected upon their own experiences as anthropologists who are disabled (Armstrong & Fitzgerald 1996; Murphy 1990; Shuttleworth & Kasnitz 1999). However, despite this slow but steady growth in ethnographic interpretations of disability, the potential impact of anthropological findings on debates within disability studies continues to remain somewhat limited. Why is this the case? Why have anthropologists not made themselves heard? Is it because of the marginal status of the study of disabilities within anthropology? Is it a consequence of the particular ways in which disabilities have been studied within anthropology? Is it a lack of cohesion amongst anthropologists as to what "culture"

[2] The work of Robert Murphy is a significant exception in this regard. Through his autobiographical account of living with a deteriorating physical disability, Murphy contributed the anthropological concept of liminality to our social and cultural understanding of disability. Drawing on Arnold van Gennep and Victor Turner's use of liminality as a term to describe the "betwixt and between" status of initiates during rituals, Murphy argued that people with disabilities experience a similar ambiguous and socially removed state (Murphy 1990: 131). However, rather than being transformed into their new social role, as van Gennep's liminal stage implied, Murphy argues that the disabled are unable to recompose themselves within the social world and therefore permanently exist at the threshold of, and oftentimes outside, the formal social system (Murphy 1990: 45, 131). Being neither sick nor well, disabled people remain ambiguous persons whose social and human status is in doubt.

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means and how it can be appropriately utilised as an analytical tool within disability studies? Or is it something to do with the nature of the debates that have developed within disability studies? Perhaps some combination of all of the above? In order to tease out the possible cause of this estrangement, I have attempted to provide a brief overview of the way in which the study of disability has developed within anthropology. I shall focus specifically on the study of intellectual disability, partly because this is the field that I am most familiar with, but also, interestingly, because it was the first type of disability to be the subject of specific ethnographic observation and analysis. As a subject, intellectual disability also raises some interesting dilemmas for disability studies, evolving as disability studies has out of the specific experiences of people with physical and sensory impairments.

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The first sociocultural attempt to understand and analyse the experiences of people with disabilities from their own perspective—to get an "insiders view" as Bogdan and Taylor (1976, 1982) later put it—was undertaken by the North American anthropologist, Robert B. Edgerton. Focusing specifically on the experiences of people with intellectual disabilities, Edgerton argued that despite the enormous amount of literature in the field, nearly all of it was from the perspective of "social workers, psychiatrists, psychologists and other medical specialists" (Edgerton 1963: 372; cf. Gillman *et al.* 1997). Edgerton sought to counter these overtly quantitative and statistical accounts through his numerous sociocultural studies that aimed to provide an insight into the lived reality of being intellectually disabled in a Western culture.

Edgerton is best known for his book, *The Cloak of Competence: Stigma in the lives of the mentally retarded* (1967), an account of deinstitutionalised mildly intellectually disabled people living in the community.[3] One of Edgerton's earliest studies, however,

[3] Edgerton's distinction between mild, moderate and severe mental retardation is sometimes confusing and contradictory. At times he argued that mildly retarded people were the casualties of sociocultural factors, including poverty, malnutrition, parental neglect and racial discrimination (Edgerton 1978: 456; Edgerton 1984a: 26-27, 37-40). However, he also argued that their incompetence was innate, and a real disability that they must constantly deal with (Edgerton 1967). In contrast, and more consistently, Edgerton wrote that those who were severely mentally retarded were undoubtedly "organically" or "clinically" so, and that their inabilities were due to this rather than any sociocultural factors (Edgerton 1984a: 26). Edgerton also stated

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analysed the potential for complex and enduring relationships between people with severe forms of intellectual disability living in a large mental hospital (MacAndrew & Edgerton 1966). However, unlike "mildly retarded individuals" who are able to "invest their behaviour with meaning" (Edgerton 1984b: 503), Edgerton went on to claim that people with profound intellectual disabilities have very little or no ability to create or respond to symbols (MacAndrew & Edgerton 1970: 28). By associating a "lack of language skills" with "impoverished cultural and social behaviour" Edgerton consequently disregarded the social and symbolic nature of profoundly intellectually disabled people's forms of expression, and ignored the means through which they meaningfully communicated and engaged with others.[4] Edgerton was also becoming increasingly interested in the issues associated with the policy and practice of deinstitutionalisation, and argued that severely intellectually disabled people cannot and do not exist in socially normal and acceptable circumstances. They were therefore not suitable candidates for community living. By extension, neither were they suitable for his study of the social and personal consequences of deinstitutionalisation (Edgerton 1967: 2-3).

In *The Cloak of Competence*, Edgerton teased out the social and personal concerns of his informants, including their relationships, self-perception and employment details. However, Edgerton was primarily concerned with how mildly intellectually disabled people coped with life on "the outs" (as life outside the institution was called), and how they adapted to living in the community. He sought to portray the interconnected effects of institutionalisation, stigma, incompetence and labelling, and concluded that these deinstitutionalised people relied heavily on the support of "non-retarded benefactors" in order to successfully cope with life outside the institution (Edgerton 1967: 193). He also argued that such people accumulated personal belongings to give the appearance of normality, invented biographies that hid their hospitalisation, and often stated that,

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that up to 75% of those labelled retarded fell into the mildly mentally retarded category (Edgerton 1984a: 26).

[4] In accordance with the dominant Western presumption that meaningful human sociality is dependent upon language, reason and intelligence (Damasio 1994; Hampshire 1956; Klotz 2001; Lloyd 1993), Edgerton and MacAndrew's interpretation consequently relegated profoundly intellectually disabled people to a status as "*less* human than some infra-human species" (MacAndrew & Edgerton 1970: 28; authors'

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unlike the severely intellectually disabled, they had been wrongly institutionalised and labelled as "retarded" (Edgerton 1967).

Despite their common denial of their intellectual disability and institutional past, Edgerton argued that his informants still had to deal with the reality of being incompetent, and that it was this which most affected their life circumstances (Edgerton 1967; cf. Luckin 1986: 94). They also had to deal with the stigma associated with being labelled intellectually disabled. As Edgerton put it:

> "The label of mental retardation not only serves as a humiliating, frustrating and discrediting stigma on the conduct of one's life in the community, but it also serves to lower one's self-esteem to such a nadir of worthlessness that the life of a person so labelled is scarcely worth living" (Edgerton 1967: 145).

However, despite his criticism of IQ scores and other measurements of skills and competencies to predict successful adaptation to the community, Edgerton did not analyse why it is that "incompetencies" associated with cognition and intelligence (in the narrowest of senses) are so readily stigmatised, nor why cognition and intelligence are so central to our Western perceptions of "normal" humanity. Nowhere did he seek to understand why it is that intellectual disability is so seemingly irredeemable in our culture; why such people are discredited in all aspects of their lives; and why we accept only certain forms of subjectivity, creativity and interaction as valid, meaningful and social. In other words, despite acknowledging that his informants had to deal with the perception that they were "not quite human" (cf. Goffman 1974: 5), Edgerton did not explore the fundamental social and cultural problem of *why* people with intellectual disabilities are perceived as such, nor how this perception ultimately shapes the way such people are treated.

This seeming disinterest in such fundamental cultural and philosophical questions about the very nature of human identity and personhood can perhaps be explained by the theoretical orientation of Edgerton's work. Although Edgerton was trained as an

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emphasis); an interpretation ironically not dissimilar to the biomedical accounts that Edgerton had previously criticised.

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anthropologist, and used ethnographic techniques such as interviews and narrative descriptions as his methods for gaining an insight into the life experiences of his research subjects, he did not draw upon contemporary anthropological theories of culture as an interpretive tool when analysing the social experiences of those who are intellectually disabled. Culture, at that time in American anthropology, was understood to be a collective, learnt and reproduced phenomenon, a "set of [symbolic] representations that shaped action and informed events" (Kuper 1999: 165). "Mentally retarded people", Edgerton argued, did not adequately learn or reproduce cultural patterns, nor could they be interpreted as a separate culture or subculture (MacAndrew & Edgerton 1970; cf. Gerber 1990: 10).[5] Therefore, despite Ruth Benedict's (1934) earlier anthropological analysis of epilepsy and abnormality as cultural concepts, and despite the fact that *all* people across the spectrum of intellectual disability utilise symbolic representations as their means for expressing themselves and interacting with others (Gleason 1989, 1994; Goode 1980a, 1980b; Klotz 2001), Edgerton turned to a different set of social theories to interpret the life stories and experiences of the people he studied. These included George Herbert Mead's (1934) symbolic interactionism, Erving Goffman's (1990, 1974) studies of stigma in relation to the power of total institutions, and Howard Becker (1963, 1964) and Edwin Lemert's (1967) analyses of labelling. Edgerton's reliance on such theories ultimately affected the direction of the sociocultural study of intellectual disability for many years, and perhaps explains the preponderance of sociologically rather than anthropologically inclined studies in the field.

Despite these drawbacks, Edgerton's groundbreaking research opened the way for the anthropological study of disabilities in general, and intellectual disability in particular. He inspired other researchers to adopt interview and narrative based techniques associated with qualitative analyses (Edgerton 1984a, 1986; cf. Atkinson & Walmsley 1999; Langness & Levine 1986). He encouraged the critical examination of social welfare policies and practices (Edgerton 1975; cf. Howard 1990; Johnson 1998), and the importance of long-term, intimate contact with research subjects (Edgerton

[5] Edgerton later changed this assessment and argued that groups of intellectually disabled people, such as those working in a sheltered workshop, could be studied as a distinct culture with their own beliefs, practices and meanings (Edgerton 1984b: 501).

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1984a, 1984c). He also emphasised the necessity of cross-cultural research (Edgerton 1970; cf. Ingstad & Whyte 1995; Jenkins 1998). One of the misguided assumptions that Edgerton sought to counter was the belief that small scale, technologically "simpler" societies will discriminate less towards people with disabilities. Through his analysis of cross-cultural perceptions and treatments of intellectual disability, Edgerton overturned this technologically and environmentally deterministic theory, arguing that there is no singular cross-cultural pattern to the ways in which such people are perceived and treated (Edgerton 1970; cf. Jenkins 1993). From such a conclusion, it could be assumed that Edgerton would emphasise the importance of culture in defining, perceiving and interpreting differences labelled as disabled. However, as was discussed earlier, this was not the case. Edgerton preferred instead to focus on social issues such as stigma, labelling and deinstitutionalisation, and chose to ignore the fundamental role that cultural meanings play in the perception and treatment of people with intellectual disabilities. And by disregarding the symbolic nature of severely intellectually disabled people's actions and interactions, and focusing solely on the information he could garner through interviews with his informants, Edgerton also ignored the role of intellectually disabled people as the producers of meaning and culture.

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An interest in the role of cultural meanings in the anthropological study of intellectual disability was stimulated by the seminal work of Robert Bogdan and Steven Taylor. Like Edgerton, Bogdan and Taylor emphasised the usefulness of qualitative research methods but, whilst acknowledging the devastating stigma associated with being labelled intellectually disabled, Bogdan and Taylor did not accept Edgerton's argument that this stigma was a result of being innately incompetent and retarded (Bogdan & Taylor 1982; Taylor & Bogdan 1998). In their book, *Inside Out: The social experience of mental retardation*, Bogdan and Taylor claimed that the "scientific aura" surrounding the term "mental retardation" hides the "subjective moral and cultural value judgements" associated with it (Bogdan & Taylor 1982: 6). For them, the term "mental retardation" tells us about society, and the methods by which people who do not fit the increasingly complex demands of modern industrialisation are perceived,

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categorised and administered (Bogdan & Taylor 1982: 9; Bogdan & Taylor 1976: 51). Drawing on Berger and Luckman's (1984) theory of social constructionism in combination with symbolic interactionism and phenomenology as their theoretical tools, Bogdan and Taylor claimed that human behaviour and action are a product of how people define and interpret the world. Therefore, rather than telling us anything about the intellectually disabled themselves, and rather than being an "objective condition", Bogdan and Taylor concluded that the term "mental retardation" was dependent upon social and cultural concepts and was fundamentally a social construction (Bogdan & Taylor 1982: 5; cf. Bogdan & Taylor 1976: 47; Taylor & Bogdan 1989: 23). As Bogdan stressed in his analysis of a 'simple' farmer accused of murder, it is the social context within which human variation is thought to exist that must be analysed, and it is the way that these differences are "thought about that matters" (Bogdan 1992: 316). Bogdan and Taylor's particular approach can therefore be said to belong to a distinct school of thought that has challenged the very concept of "mental retardation" as a meaningful category at all.

Although not absolutely denied, difference for Bogdan and Taylor is primarily a product of social definition and categorisation. What is important is the meaning attributed to difference, especially through the perspectives of those who are not disabled, and the effects that this then has on those who have been labelled this way (Bogdan & Taylor 1998: 245). However, while these meanings may differ, and while social, cultural, historical and material factors have a profound affect on the lives of all those who are labelled intellectually disabled, such structures and constructions do not constitute the entirety of intellectually disabled people's lives. Interpretations that only take these aspects into account, and which perceive the experience of intellectual disability as solely a product of sociocultural structures and constructions, disregard the fact that intellectual disability is an ontological reality that makes a real difference to one's experience of being in the world. Rather than examining the life world that this difference gives rise to, researchers who adopt a constructionist perspective ignore the real implications of difference as *both* productive of the sociocultural world *and* the product of it.

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An emphasis on social definitions, constructions and meanings has, however, become increasingly prominent within more recent anthropological accounts of intellectual disability. In such constructionist analyses, which include cross-cultural, post-structural and deconstructionist accounts, the focus is solely on categories, constructs and labels, as well as social institutions and structures, and how these impact upon the interpretation of intellectual disability (Branson & Miller 1989, 1992; Cocks & Allen 1996; Connors & Donnellan 1993; Ferguson 1987; Johnson 1998; Lea 1988; Longmore 1985; Manion & Bersani 1987). Such approaches to the study of intellectual disability take these constructions as already given, as already determining the social experiences of intellectually disabled people. They seek to either explore the social and individual consequences of discursive practices (Cocks & Allen 1996; Johnson 1998), or to "release" intellectually disabled people from the negative grip of these constructions by deconstructing the very constructions that supposedly constrain them (Branson & Miller 1989; Ellis 1998). They also tend to use the variability of cultural and historical concepts of "mental retardation" as proof of its inherent emptiness as a concept (Manion & Bersani 1987).

Unwittingly, and despite their criticism of clinical and institutional practices, such constructionist analyses tend to perpetuate the consequences of these practices by ignoring the fundamental sociality of intellectually disabled people. Rarely do any of these more recent accounts seek in any way to enter into the lived realities of people with intellectual disabilities as persons whose lives are much more, or other, than the products of these supposedly overarching and deterministic constructs. We tend to learn more about what they signify and represent as objects of sociocultural constructions rather than who they actually are, as human subjects creating meaning and engaging in relationships with others. In fact, unlike Bogdan and Taylor's groundbreaking but ultimately problematic attempt, rarely do we hear the voices or gain access to the experiences of people with intellectual disabilities at all. As a consequence, we tend to remain outsiders, unable to fully grasp or engage with the lived realities of such people negotiating with the cultural values and beliefs that surround them (cf. Whyte 1995: 240-241). We gain little if any insight into how the world is made meaningful by them, and of the symbolic nature and potential meaning of their actions and behaviours. This

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ultimately denies people with intellectual disabilities their role as active participants in social life. It also denies them their status as people who produce culture.

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The first serious challenge to the omission of people with intellectual disabilities as producers of meaning and culture has been through the work of David Goode (1980a, 1980b) and John Gleason (1989, 1994). While drawing on the methodological principles of participant-observation and qualitative analysis that Edgerton, Bogdan and Taylor all encouraged, the work of Goode and Gleason provides us with a different and, I would argue, potentially more significant insight into the lives of all people with intellectual disabilities. Rather than focusing solely on the impact of social policies, the stigma of labelling, or the social construction of intellectual disability, Goode and Gleason both emphasised the centrality of interactions and relatedness in their accounts of intellectual disability. They sought, albeit in their different ways, to gain some insight into the intentional, purposeful and meaningful actions and interactions of people with severe, profound and multiple disabilities.

The subject of one of David Goode's earliest studies was "a congenitally deaf-blind and retarded girl" called Chris who lived in a state hospital ward. Although at first Goode attempted to simulate Chris' deafness and blindness he realised that, as someone who already knew the world as a seeing-hearing person, it was impossible for him to ever really know how she experienced the world. He instead decided that "only intimate and persistent interactional contact . . . would be likely to enable [him] to enter [her] world" (Goode 1980b: 187-198). Consequently, Goode developed "interactional strategies", which included mimicking Chris' repetitive behaviour as well as her perceptual, tactile engagement with the world, in order to build up a basis for intersubjectivity on Chris' terms.

Through such interactions Goode discovered that Chris responded enthusiastically to sound stimulation, especially to the rhythm and frequency of music. She also responded to touch and any form of physical interaction, using her tongue for sensory gratification and to gain information about objects in her world. As well as these, Chris

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exhibited "autostimulatory behaviours", such as finger flicking, rocking and head swinging, in response to light and sound. On the basis of these observations, and by mimicking Chris' actions and engaging with her through these actions, Goode recognised that there was an inherent purpose, pattern and rationale to Chris' behaviour; the seeking of rhythmic sensory stimulation and gratification (Goode 1980b: 197-199). Although Chris lived in a significantly different perceptual and cognitive world, and did not recognise or utilise linguistic symbols, Goode argued that she was still capable of communication and that her world was ultimately meaningful and a direct reflection of her disabilities (Goode 1980b: 193-198).

Goode's interactional encounters with Chris broke new ground in the anthropological study of intellectual disability. It represented the first "inside account" of a severely intellectually and physically disabled person's world. Rather than embodying culture and communication in linguistic capabilities and recognisable cultural enterprises, and rather than interpreting culture as solely the constructs that define and categorise difference, Goode acknowledged that it was possible to develop a sense of a shared world through such purposeful and intimate interactions (Goode 1980b: 203-205). He also recognised that it was possible to find intention and meaning in such a world. Through entering Chris' world on her own terms, Goode was able to establish a meaningful and mutual basis for their relationship. He was able to see her as the producer of meaning and culture.

Analysis of the inherent meaning and significance of the symbolic systems that people with intellectual disabilities utilise and create in their everyday lives requires long-term and intimate engagement with the people in question. This is a methodological approach central to anthropology. While anthropologists also pursue their own particular theoretical agendas, and while fieldwork practices are to some degree affected by these agendas, the emphasis on long-term fieldwork allows for the emergence of observations, themes and theoretical orientations that fundamentally draw upon interactions and relations with informants. David Goode's early research was based upon such practices. Unfortunately, he ultimately abandoned the early insights that he gained in favour of a social constructionist perspective that emphasised the

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impact of intimacy and relatedness on "socially produced identities" (Goode 1984, 1990).[6]

John Gleason, on the other hand, utilised such anthropological techniques throughout his work. His book, *Special Education in Context: an ethnographic study of persons with developmental disability* (1989), provides an in-depth account and analysis of the possibilities for meaningful interaction between people with severe and multiple disabilities. As part of his fieldwork research, Gleason spent five years observing the social interactions of a group of residents at a state school for physically and intellectually disabled children in North America. Through this long-term study Gleason sought to analyse the consequences of therapeutic and special education practices, including changes brought about by deinstitutionalisation and normalisation policies.

Gleason argued that the way people with severe and multiple disabilities engage with one another, and indeed with others who are non-disabled, is generally perceived as aberrant, meaningless and in need of transformation (Gleason 1989: 62, 256-257; cf. Gleason 1994; Goode 1980b: 192-193; Klotz 2001; Lea 1988; Taylor 1998: 198-199). This dominant and conventional clinical view of disability has informed contemporary normalisation practices and fundamentally affected the way in which people with intellectual disabilities are able to interact with eachother. While Gleason was interested in uncovering the consequences of such policies, his main objective was to illustrate the means through which such people develop their own way of relating to one another. Through his description of the interactions taking place between two non-verbal

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[6] In a similar vein to Taylor and Bogdan's (1989) "sociology of acceptance", Goode (1984) developed the notion of "socially produced identities". For Goode, "radically different identities" are produced as a result of differences between intimate, accepting relationships and clinical, objective perceptions (Goode 1984: 229). He argued that while such clinical perceptions view severely mentally retarded people as negative and entirely deficient, subhuman beings, familiarity and intimacy allow instead for the perception and recognition of such people's human attributes and competencies (Goode 1984: 244-245). Therefore, while intimacy may change the perception of, and form of engagement with, a severely intellectually disabled person, it is the social construction of intellectual disability and the symbolic interaction of meaning based upon these constructions that is ultimately important. Just as Edgerton, and Bogdan and Taylor, had done before him, Goode emphasised and perpetuated sociological arguments concerned with the effects of labelling and the social construction of identity. Goode also later stipulated that the persons he studied "do not use symbolic language" (Goode 1990: 30). This preoccupation ultimately superseded Goode's innovative and highly insightful account of his interactions with Chris, whereby the possibility of recognising, engaging with, and analysing the potential meaning of a severely intellectually disabled person's behaviour was developed and mediated precisely through the course of mutual interaction.

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multiply disabled boys called Thomas and Daniel, Gleason revealed their innate potential for meaningful behaviour. Rather than correcting the boys' behaviour and forcibly moving them away from one another as they rolled around on the floor in a seemingly meaningless and chaotic manner (as the staff were instructed to do), Gleason allowed Thomas and Daniel to interact as they wished. By adopting a methodology that maintained a sense of the context within which their actions and interactions took place, Gleason discovered that the boys' were actually engaging in meaningful and intentional behaviour. He realised through his observations that Thomas and Daniel had developed shared and learned patterns of engaging with one another. Therefore, rather than imposing normative standards of behaviour and interaction based on a clinical model of deficit and dysfunction, Gleason interpreted the relationship between these boys' particular and unique forms of interaction and function as central to the production of meaningful content (Gleason 1994: 247-249, 1989: 79, 106, 152).

While Gleason's approach illustrated the possibility of discovering meaningful patterns and behaviours in the actions and interactions of profoundly intellectually disabled people, his focus on relations between those who are profoundly disabled, rather than between people across the difference of dis/ability, still tends to isolate severely intellectually disabled people within their own other worlds. The challenge that is necessary to fully respect and acknowledge the meaning and innate humanness of all people with an intellectual disability people actually requires negotiating this difference, and entering into the life world of the people in question, just as Goode (1980b) had done in his earlier research with Chris (cf. Atkins 1998; Klotz 2001). In order to fully account for why it is that people with intellectual disabilities are treated and perceived in the way that they are it is also necessary to disentangle the cultural meanings embedded in so many of the practices and policies directed towards them. Gleason began such an analysis in his work. However, in order to gain a more cohesive and potentially influential insight into the significance of these meanings, an analysis of the historical and cultural nature of what it means to be a human and fully cultural person is necessary. While I have attempted this in my own research on the interpretation of intellectual disability in Western cultures (Klotz 2001), it is within cross-cultural

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investigations of intellectual disability that some of the most exciting anthropological research is being undertaken.

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Although many cross-cultural accounts have sought to determine different cultural explanations for how or why a "disability" became manifest—such as interpretations based on the Hindu concept of karma, the Australian Aboriginal belief in social and ritual transgression, African notions of witchcraft, the Christian belief in sin, or the Islamic acceptance of fate (Armstrong & Fitzgerald 1996: 264-267)—a number of recent researchers have begun to explore the very notions of humanity and personhood upon which such interpretations are founded (Armstrong & Fitzgerald 271-274; Jenkins 1993, 1998). The link between notions of personhood and disability are both culturally diverse and internally variable (Armstrong & Fitzgerald 1996: 271; Ingstad & Whyte 1995). In Western cultures, personhood is often defined in "egocentric" terms, based as it is on notions of independence, autonomy, personal success and self-reliance. Such cultures also value the individual attributes and competencies associated with productivity, literacy, and intelligence. In contrast, cultures that are defined as "sociocentric" tend to value group-oriented attributes such as sociability and interdependence (Armstrong & Fitzgerald 1996: 271-275; cf. Davies 1998; Devlieger 1998; Jenkins 1998; Klotz 2001; Nuttall 1998; Whyte 1998). While a complex interdependence of individual and social attributes exists in all cultures, it is still possible to define different cultures within these broad descriptive terms. The impact that these different cultural notions of personhood has on the ways in which disabilities are perceived, interpreted and treated reveals the myriad ways in which disability is constructed, and the fundamental impact that such values, beliefs and interpretations have on the lived experience of disability. To illustrate, I shall outline a number of different ethnographic interpretations of the interconnection between personhood and intellectual disability. These include Patrick Devlieger's (1998) descriptions of "incompetence" within the Songye of Zaire and the Shona of Zimbabwe, Susan Reynolds Whyte's (1998) analysis of learning difficulties amongst the Nyole of rural Uganda, and Mark Nuttall's (1998)

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account of the different ways in which slow learners are perceived by the Inuit of Greenland.

Patrick Devlieger has argued that amongst the Shona and Songye peoples of south eastern Africa, personhood is defined as the ability to interact with others within the broader social context. While this may seemingly exclude those who are less socially competent, such interaction is fundamentally based upon the wider social network of relationships into which people are born. As an extension of this, any disruption to a person's physical or mental abilities is interpreted within broader cosmological terms of "wronged relationships" with nature, relatives, ancestors and God. Thus the social and the cosmological serve to reinforce one another in such a way as to provide both a moral framework for behaviour and a means for dealing with disruptions to the desired order. In such cultures, witchcraft is often used to restore "relational embeddedness", as the social domain of relationships are perceived as being in need of restoration rather than the individual self. (This is in stark contrast to the Western bio-medical model that emphasis individual physiology and rehabilitation as the causes and cures for disability.) Even an individual's social and personal competencies are not divorced from the social context within which they exist. Competency is always perceived as the way in which an individual creatively deals with their particular situation, such that, as the Shona proverb states: "People with disabilities are clever, they have strategies, they dance whilst leaning against the wall" (Devlieger 1998).

Like Devlieger, Susan Reynolds Whyte has also spent many years researching the meaning of disability within East African cultures, although in this particular example her focus is on the Nyole people of rural Uganda. Whyte emphasises the connections between local notions of personhood, agency and self, arguing that interpretations of competency and sociality take on different forms in different cultures. As Devlieger also discovered, competency among the Nyole is "a property of social relations" rather than an individual attribute. The stress on kin relatedness as the primary means of defining personhood means that all persons have a place whatever their individual attributes and skills. In this sense, acceptance and belonging are not only accorded by one's immediate network of kin, but by the whole community, who by

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extension recognise the social place of all persons. While personhood amongst the Nyole is also based on the capacity to learn, assist others, be civil, converse with others and be inventive, Whyte emphasises that these attributes are all based on the recognition and respect accorded to others as part of the broader social system. Ones' value as a person is based on a mixture of these attributes such that intellectual cleverness or financial success do not of their own accord become necessary prerequisites for acceptance and respect. The total character of a person is taken into consideration, as is the situation within which a person exists and responds to the world and those around them. In this sense, a Nyole person still has the potential to have a place, a role and social value whatever their individual levels of "competence" (Whyte 1998).

Mark Nuttall, on the other hand, has studied the Inuit people of Greenland in order to disentangle the effects of non-indigenous models of intellectual incompetence on local Inuit models of personhood. The Inuit live in a harsh and unpredictable environment, dependent on seals for both food and trade. Their elaborate social and moral codes, as well as their concepts of personhood, reflect this interdependent relationship, emphasising the importance of a seal diet to physical and spiritual wellbeing, the skills as a hunter necessary to maintain such a diet, and the knowledge of places and persons within which their society is embedded. The Inuit emphasise a continuity between the social, natural and supernatural worlds, and, whilst they recognise different levels of incompetency, do not exclude individuals on the basis of these. For the Inuit, a person consists of a body, a soul and a name, where the name has both a social and a spiritual dimension. Full personhood is a consequence of being named, of being socially incorporated into the wider network of relationships. A child's name is inherited from someone previously deceased, and not necessarily from someone who is biologically or affinally related. This accords the new child a whole range of social relationships based on both one's own and on the previous person's kin networks. To be named is to belong, both to a people and to a place. In this way a person is not separated from either the social or the natural environment.

As Nuttall points out, devastating consequences occur when such notions of identity clash with the values and practices associated with Western models of

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personhood and incompetency. The Danish educational system, under which the Inuit are forced to exist, demands that a person who is slow or intellectually disabled be removed from their familial environment and placed in special educational facilities which are often far removed from the local community. This practice undermines Inuit culture. It disrupts traditional learning patterns based on the passing down of parental knowledge, prevents children from attaining the necessary spiritual and physical sustenance provided by seal meat, and destroys the social identity of individuals that are fundamentally embedded in both a knowledge of, and engagement with, people and places (Nuttall 1998).

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While this is just a brief overview of the history and range of anthropological studies of intellectual disability, it hopefully provides some picture of the different ways in which anthropologists have sought to understand the nature of disability as a cultural phenomenon. Having provided this overview, I now wish to explore what these studies have to offer to the growing discipline of disability studies. I would argue that some of the innovative forms of research outlined above have the potential to provide new avenues for debate and exploration within disability studies. However, apart from the contributions of those such as Bogdan, Taylor, and the later work of Goode to the social construction of disability there has been little common ground between the two areas of research. This is a product of both the particular concerns of disability theorists, and the specific orientations of anthropologists. It is also, possibly, a consequence of the very different ways in which anthropologists interpret culture.

Although there are obviously many important insights that the social model of disability has brought to our understanding of what it means to be labelled disabled there are some serious limitations to this approach. Even the analysis of the social consequences of impairment, whilst offering personal insights into the lived experience of disablement, in many ways perpetuates some of these problems. By constituting social constructs and structures as the primary cause of problems associated with being disabled, disability scholars have often denied the real and ontological implications of living with intellectual, physical and/or sensory impairments. Consequently, they have

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often ignored the personal and social implications of differences that are undeniably grounded in the body and/or the mind; differences which constitute a significant part of the experiences, perceptions and identities of all of us, including those who are disabled (Hughes & Paterson 1997; Meekosha 1998). While the experience of impairment is always entangled in a complex web of social and cultural constructs and structures, to deny the role of the body and/or mind in the formulation of these experiences ultimately undermines the quest for the real acceptance of difference in whatever form this takes. In this sense, the whole foundation of the social/medical dichotomy upon which disability studies has been built needs to be re-examined (Atkins 1998; Kasnitz & Shuttleworth 1999; Klotz 2001; Singer 1999; cf. Ellis 1998).

The emphasis in disability studies on the "dis-abled" body in opposition to "able-bodiedness", and on disability as a physical and/or sensory rather than an intellectual experience, also has problematic implications for those whose impairments are intellectual. As Anne Chappell (1998: 214-216) argues, intellectually disabled people have been marginalised within the discourse of disability studies due to this emphasis on the body. It is, she claims, one of the consequences of including all forms of impairment within a singular analytical category as "disabled". Rather than critiquing the social model in total, however, Chappell (1998: 212) suggests that the particular experiences of intellectually disabled people should be included within this model of disability—along with all those other variables such as age, gender, ethnicity, class and sexuality which make the experience of disability diverse and specific.

However, while the experiences, aspirations and perceptions of people with a physical disability may approximate those of people who are "able-bodied" to some degree, the ways in which people who are intellectually disabled experience and perceive the world are often entirely different and unique. While people with milder intellectual disabilities may be capable, and indeed desirous, of conforming to some of the social norms, expectations and aspirations that the "able-minded" pursue, the social, perceptual and intellectual world inhabited by people with severe intellectual disabilities does not generally conform to such normative ways of behaving and interacting. Such people are rarely able, or indeed willing, to participate in "normal"

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social endeavours such as work and recreation (Atkins 1998; Gleason 1989; Klotz 2001). Nor are many of them aware of, or even bothered by, their own difference to others. In this sense, people with severe and profound intellectual disabilities do not self-consciously struggle with the expectations of "normal" society. While this does not exclude all people with an intellectual disability from being subject to enormous social pressures to change who they are and how they behave, most people with an intellectual disability continue to act and behave according to their own particular and idiosyncratic natures. For severely intellectually disabled people these are often unique, highly contextual, reflective of a very different intellectual and creative process as well as a very different way of being in the world.

The theoretical and methodological tools that are required to understand and engage with these life worlds, however, are not those generally used by disability theorists. The focus on labels, constructs, structures and meanings, useful though these are for understanding the impact of sociocultural practices and attitudes, does not allow us to actually enter into intellectually disabled people's worlds and relate to them as people who are already fully human and encultured beings. An anthropological enterprise based upon long-term fieldwork does, however, have the potential to encourage the development of such relationships. Edgerton was one of the first to undertake such an enterprise, although his engagement with people with mild intellectual disabilities circumvented the issues that arise when encountering people who are not able to articulate and reflect upon their experiences. Edgerton's dependence on sociologically informed theories of labelling and stigma, and his concern with the consequences of social practices and polices, also set the agenda for the majority of sociocultural studies of intellectual disability. Bogdan and Taylor picked up on this concern with labelling but took it even further than Edgerton, criticising the whole foundation of the term "mental retardation" as a meaningful category at all. However, like Edgerton, they also limited the possibilities of their interpretations by focusing almost exclusively on the issue of labelling, on culture as the producer of social meanings, and on the experiences of people with mild rather than severe intellectual disabilities. It was only through the early work of Goode, and in Gleason's accounts, that serious attempts were made to analyse the lived reality of people with severe and

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profound intellectual disabilities. In their different ways, both Goode and Gleason sought to portray the social and meaningful nature of severely intellectually disabled people's life worlds and to present them as people who are also the producers of culture.

However, while both Goode and Gleason accepted the inherent meaning in the behaviours and interactions of people with severe and profound intellectual disabilities, neither of them utilised the insights that they gained to question the very foundation of our cultural notion of what constitutes such meaning. Yet it is upon such social and cultural foundations that our perception of ''normal' and 'abnormal' personhood is built. In this sense, the cross-cultural study of intellectual disability offers perhaps one of the most exciting avenues for research, allowing for both an analysis of categories of personhood, normality and humanness as cultural categories, whilst at the same time providing a rich analytical description of the ways in which differences are culturally negotiated and mediated.

If anthropologists wish to offer something new to disability studies, they need to articulate the importance of the culture concept as a fundamental aspect of disability. They need to acknowledge the important insights of the social model of disability, which emphasises the socially constructed nature of disability as a cultural product. However, they need to do so without losing sight of the unique contributions that anthropologists can make to the field through ethnographic accounts that give priority to the lived experience and negotiated meaning of "disability" in whatever form these become manifest. Through such multivaried approaches to the use of culture as an analytical tool, and by juggling the concept of culture as something which we both inherit and create, anthropologists are in a position to both critique and enhance our understanding of disability as a complex social, cultural and biomedical phenomenon.

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