Chapter Five

A Sociocultural Phenomenon

Since in Man the predominant feature is Mind,
and since it is by its development and evolution
that human progress has taken, and must take, place,
it is clear that the question of its disease, and particularly of its defect,
is one of supreme importance to the statesman,
the sociologist, the philosopher, and the whole community.

Tredgold & Soddy

As a consequence of these clinical assumptions, psychological and medical interpretations of intellectually disabled people have placed such people beyond normal or autonomous sociality. In sum, this situation has meant that intellectually disabled people are only ever professionally "known" in terms of their abnormalities or problems, be they physical, intellectual and/or behavioural. Such a "case history" approach not only informs the way that intellectually disabled people are perceived and treated but it also limits responses to them (Gillman et al. 1997). Despite more recent concerns with assessing intellectually disabled people's potential for social adjustment and competence, and acknowledgments that they can learn and develop social skills, such practices are still limited by institutionalised environments.

The overwhelming dominance of this clinical and institutional approach to intellectual disability has meant that such people's pre-existing capacity for sociality has rarely been acknowledged. Nor have their lives been readily examined from a sociocultural aspect. Intellectually disabled people may have
constituted a social concern or problem but they were not considered social beings worthy of social analysis. This neglect was influenced by the assumption that reason and intelligence were the necessary attributes for meaningful sociality. Without them, it was impossible to be a normal human, let alone a social person. However, just as concern for the proper diagnosis of borderline retardation or feeble-mindedness precipitated the development of intelligence testing, it was an interest in the life circumstances of mildly retarded individuals in the community that precipitated one of the first sociocultural studies of intellectual disability. Robert B. Edgerton (1967) is the person associated with the first ethnographic study of mentally retarded people, and while he inspired a number of analyses of intellectual disability from a cultural and cross-cultural perspective, to this day the study of intellectual disability still remains a relatively minor field within the social sciences. Following Edgerton’s example, many sociocultural researchers in the field of intellectual disability have analysed the stigma and social consequences of being labelled mentally retarded. They have also focused on social welfare issues such as deinstitutionalisation, socialisation and community adaptation. In the first section of this chapter I outline the contribution of Robert Edgerton's research to the sociocultural field of intellectual disability, both through his own research and through those who were inspired by his approach. I then explore the uneasy alliance between these sociocultural studies of intellectual disability and disability studies—a multidisciplinary field of research which emerged at around the same time—especially with regards to critiques of the medical model of disability.

While the sociological and social welfare issues that Edgerton researched are important, central as they so often are to the life experiences of intellectually disabled people, there is often a tendency to focus on these at the expense of analysing other ways in which intellectually disabled people experience and
make meaningful their lives. The work of Robert Bogdan and Steven Taylor (1982) represented an important and significant shift in the sociocultural analysis of intellectual disability. Through the words of two mildly retarded informants Bogdan and Taylor provided the sociocultural field of intellectual disability with an "insiders view" of the lived experience of mental retardation. Bogdan and Taylor were also critical of Edgerton's uncritical acceptance of the clinical interpretation of mental retardation, arguing instead that such clinical interpretations must be analysed as a social construction; an approach which aligns their work more closely with disability studies. However, while the clinical model inadvertently denies intellectually disabled people's capacity for human sociality, the social constructionist model ignores the fact that intellectually disabled people are more than just the products of social constructions, projections and meanings. In the second section of this chapter I outline the contribution of Bogdan and Taylor, and show how their work has influenced contemporary social analyses of intellectual disability as a social construction.

As a consequence of Bogdan and Taylor's phenomenological method, a third "school" of thought has emerged in the sociocultural field of intellectual disability. In the final section of this chapter I explore in detail the work of David Goode (1980a, 1980b, 1984, 1990) and John Gleason (1989, 1994), who both emphasise issues of intimacy, relatedness, communication and meaning in their research with intellectually disabled people. Unlike Edgerton and Bogdan and Taylor's accounts, which predominantly focus on the experiences of mildly intellectually disabled people, both Goode and Gleason have focused their research on relationships with and between severely intellectually disabled people. While their concern with intimacy and relatedness has resonances with my own analysis, there are also significant differences, both between them, and between their work and my own. By comparing the difference between clinical
and intimate relationships with severely retarded persons, and their connection to differences in perceptions of such people's attributes and capabilities, Goode has argued that identities are socially generated. His work consequently remains partially within a social constructionist paradigm. Gleason, on the other hand, has focused his attention on the possibility of meaningful interactions between severely intellectually disabled people and uses these observations to critique some practices in special education. He argues that the pathologisation of intellectually disabled people as socially abnormal prevents educators from recognising the intent and meaning in such people's actions.

My own analysis of the clinical interpretation of intellectual disability as a product of the symbolic scheme of reason and normality seeks to understand why such people are perceived as socially abnormal and what the institutional consequences of this perception are. I also emphasise the fundamental sociality of severely intellectually disabled people and seek to interpret intimate and meaningful relationships with them by acknowledging that mutuality, interdependence and interrelatedness can constitute their social life. I argue that it is through the negotiation and mediation of symbolic systems that the mutuality and sociality of intellectually disabled people is manifest and recognised.
Labelling and Stigma: The work of R. B. Edgerton

In 1963 Robert B. Edgerton criticised the fact that, despite the enormous amount of literature in the field of intellectual disability, nearly all of it was from the perspective of "social workers, psychiatrists, psychologists and other medical specialists" (Edgerton 1963: 372). As such, he went on to argue, it only ever "consists of psychometric reports, demographic analyses, observations from the school, medical office or clinic, and short interviews with the retarded person or his family" (Edgerton 1963: 372; cf. Gillman et al. 1997). Edgerton

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1 Robert Edgerton trained as a graduate student in anthropology at the University of California at Los Angeles (UCLA) during the 1950s. He did his doctorate there under the tutelage of Walter Goldschmidt and then taught in the Department of Psychiatry and Anthropology at UCLA from 1962. Edgerton was also instrumental in the development of the Socio-Behavioural Research Group which was part of the Mental Retardation Research Centre at UCLA—one of the 12 university based research centres to exist in the United States in 1984 (Edgerton 1984a). Edgerton's main area of interest was psychological anthropology, which at that time was influenced by neo-positivist studies of the relationship between personality development, society and culture. His doctoral research was a projective study of the Menomini Indians of Wisconsin; a study that sought to elucidate whether or not "Menomini values, like their patterns of personality, were equally predictable in terms of an acculturative process" (Edgerton 1978: 449-450). After completing doctoral research Edgerton joined Goldschmidt's research team which was attempting to determine the effects of ecological and economic changes on cultural adaptation in East Africa. However, Edgerton had already begun doing research with mentally retarded people by this time, studying the effects of institutionalisation, and the institutional process, on personality and behaviour. It is this area of research for which he has become best known.

2 It is arguable that there has been little change in the intervening period since Edgerton made this statement. Hugh Mehan points out in his study of educational handicaps that the medical model is still pervasive and dominant. As he puts it: "When mental states are equated with physical states, educational handicaps become equated with diseases" (Mehan 1988: 80; cf. Ryan & Thomas 1987). Despite the growth of literature exploring intellectual disability from a qualitative and sociocultural perspective, the majority of research is still biomedically and quantitatively inclined. The Australian Journal of Intellectual and Behavioural Disability only ever has such quantitative analyses, and while the social study of disabilities is starting to make a mark on the academic scene in Australia, it is still only through informal gatherings of like-minded researchers (such as the Social Relations of Disability Research Network which has monthly seminars at the University of New South Wales) rather than through any formal journal or school. Although disability studies has become more established in the academic scene in the United Kingdom and the United States
sought to change this through his many sociocultural studies of the lives of mentally retarded adults, although he is best known for his ethnographic account of deinstitutionalised people entitled *The Cloak of Competence: Stigma in the lives of the mentally retarded* (1967).

The most significant feature about *The Cloak of Competence* was that for the first time the lives of mentally retarded people, as conceived and articulated by them, were deemed to be worthy of social analysis. There was, however, still an underlying social welfare concern in Edgerton's ethnography, especially with regards to the problems associated with deinstitutionalisation and social adaptation. Despite this, Edgerton gave to his subjects complex, multifaceted, and dynamic social and psychological experiences, transforming them from objects of study into subjects with their own, albeit problematic, points of view (Gerber 1990).³ Where previous studies had focused primarily on external quantitative assessments of how mentally retarded people adjusted to the community, Edgerton filled a void by providing an ethnographic account of their everyday lives, thoughts and emotions, and how they felt about being retarded and living in the community (Edgerton 1967: 7-8; cf. Edgerton 1963; MacAndrew & Edgerton 1970 for an account of the everyday lives of institutionalised adults).

Although Edgerton was trained as an anthropologist, and used ethnographic techniques such as interviews and narrative description as his means for understanding the life experiences of his subjects, he did not draw upon contemporary anthropological theories of culture as his theoretical tool. 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). Consequently, despite Ruth Benedict’s (1934) earlier anthropological analysis of epilepsy and abnormality as cultural concepts, and despite the fact that intellectually disabled people do utilise symbolic representations as their means for interacting with others, Edgerton turned to Erving Goffman’s symbolic interactionism and his analyses of labelling, stigma and total institutions to interpret the life stories and experiences of the people he studied.

In the early 1960s Goffman had applied the technique of participant-observation in his study of the stigmatising effects of total institutions on an individual’s identity and self-esteem (Goffman 1990 [1961]; Goffman 1974 [1963]). While Goffman (1990 [1961]: 130) acknowledged that those on the "backwards" (i.e. the mentally retarded) could have "a livable and continuously

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4 In characteristic style, Edgerton changed this assessment and later argued that groups of mentally retarded people such as those working in a sheltered workshop could be studied as a distinct culture with their own beliefs, practices and meanings (Edgerton 1984d: 501).

5 In 1934 Ruth Benedict published an essay entitled "Anthropology and the Abnormal". Rather than dealing with questions of why abnormalities occurred or how they could be treated, the whole notion of abnormality as a cultural phenomenon was instead put under scrutiny. Through an analysis of cultural attitudes towards abnormalities such as epilepsy, Benedict concluded that the perception of such conditions is culturally relative and based upon different values and interpretations of both human behaviour and social roles (Benedict 1934). Benedict argued that the American Indian cultures which she studied valued the trance states that occur with epileptic seizures and associated them with the authoritative and honoured role of spiritual mediums. In contrast, Western cultures perceive epilepsy as "blots upon family escutcheon and as evidences of dreaded disease" (Benedict 1934: 61-2). Where the latter are branded "abnormal and reprehensible", the former interpretation of epilepsy makes it "an essential attribute of ideal man" (Benedict 1934: 72). Consequently, Benedict argued, both normality and abnormality are culturally and morally defined, such that 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).
meaningful social world" once seen from the inside, he stopped short of analysing their experiences, or "moral careers", claiming that such people lacked the complexity and learning capacity essential for self preservation through role-playing, denying, and passing. In contrast, Edgerton argued that mildly mentally retarded people could and did have the capacity to develop ways of dealing with their stigmatised identity, and that they do attempt to pass as normal in efforts to conceal the stigma of their discredited identity (Edgerton & Sabagh 1962; Edgerton 1967; cf. Gerber 1990: 11-14).

Goffman had also been influenced by symbolic interactionism, a theory of social life most readily identified with the social psychology of George Herbert Mead. Mead (1934: 1-24) argued that humans are distinguished by their capacity for language, for symbolic representation, and that meaning, rather than being inherent in things or a consequence of abstract rationality, emerges through the interaction of the self with society. One sees oneself in relation to others, and how others perceive us, but also through the social roles that we enact. Therefore, it is the social meanings that people attach to the world and others that determines their actions (Taylor & Bogdan 1998: 11) As Kathryn Pyne Addelson puts it (in paraphrasing Herbert Blumer, a student of Mead’s who gave to symbolic interactionism its specifically sociological dimension): "It is the social process in group life that creates and upholds the rules, not the rules that create and uphold group life" (Addelson 1991: 81).

In the 1960s Howard Becker (1963, 1964) and Edwin Lemert (1967) applied some of the insights of symbolic interactionism to their analyses of the social processes by which certain behaviours are labelled as deviant. They theorised that the problem of deviancy lay not in the act itself but within the institutionalised and professional definitions and interpretations of behaviour that labelled as deviant those behaviours which deviated from the norm. In this way the process of labelling both produced and reinforced deviant behaviours
in a self-perpetuating, circular relationship such that a person incorporated this definition into their self-image and played out the deviant role assigned to them (Whitehead 1993: 49-50; cf. Conrad & Schneider 1985; Ferns 1993: 135-6; Mehan 1988).

While Edgerton incorporated the theories of labelling and symbolic interactionism in his analyses of mental retardation, he was critical of the application of deviancy theory to the experiences of mentally retarded people. The dominant Parsonian/Durkheimian viewpoint was that deviance was a product of disturbances in the social equilibrium rather than a natural product of human nature. This "oversocialized view of man" (as Dennis Wrong put it; cited in Edgerton 1978: 445), claimed that humans internalise the rules, values and laws of society and culture and that they conform to these in order to sustain social harmony and self-esteem (Edgerton 1978: 445-449). Alternatively, as Becker and Lemert argued, deviancy is a social category that serves to support the status quo or to maintain group identity in contrast to dominant social expectations (Edgerton 1970: 538-539). Edgerton was frustrated with both these interpretations of deviance, arguing instead that it was a complex process which involved both deviant acts and deviant persons, and that the causes must be sought in the interaction of sociocultural environments with human nature (Edgerton 1978: 470). With regards to mentally retarded people, however, Edgerton stated that the metaphor of deviance was inappropriate because such people do not consciously or intentionally deviate from the status quo (Edgerton 1970: 539; 1967: 209). Consequently he preferred to use the term incompetence, and focus on issues of stigma and labelling, rather than adhering to the theoretical concept of deviance.

Despite this general interest in competence, stigma and labelling, Edgerton's early forays into the field of intellectual disability were somewhat different in their preoccupations. They focused instead on the social relations and
friendships of retarded individuals. One of these early studies was a profile of the "complex social relations" that "elite" patients in a mental hospital had with one another (Edgerton 1963). These "elite" patients were comprised of a subgroup of inmates of mainly Black and Mexican-American people from low socioeconomic backgrounds. They were not necessarily the "high grade" inmates (the 21% who were the highest functioning with an IQ above 50)\(^6\) but were defined by their shared, often self-appointed, status as delinquents (Edgerton 1963: 374). The elite patients set themselves apart from the other inmates, claiming that they were not mentally retarded and therefore should be in a prison or home with other delinquents rather than a mental institution.\(^7\)

In another early paper Edgerton and Craig MacAndrew argued that, despite the general perception of severely mentally retarded people as possessing "only the barest rudiments of those qualities which are taken to be peculiarly human", they do have the capacity for enduring and elaborate friendships with one another (MacAndrew & Edgerton 1966: 613). Through a description of a long term, emotional and "extraordinarily intense and pervasive friendship" between two institutionalized males, Edgerton and MacAndrew argued that severely retarded people do engage in complex relationships that "are testimony to the essentially human character of even the most retarded among us" (MacAndrew & Edgerton 1966: 620). However, unlike mildly retarded individuals who have the capacity to "invest their

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\(^6\) The other groups within the institution, the "low grades" and "middle grades" are defined by having an IQ below 20 (30% of inmates) and an IQ between 20 and 49 (49% of inmates) respectively (Edgerton 1963: 373).

\(^7\) Interestingly, especially with regard to Benedict's earlier analysis of abnormality, one of Edgerton's concerns in this essay was with the issue of "normality" in social relationships and behaviour. He posed a number of questions about the "intra- and inter-personal nature of 'normality'", emphasising the seemingly "normal" and complex nature of the behaviour and social relationships of this elite group, arguing that low IQ does not necessarily prohibit a person from engaging in appropriate and competent social behaviour (Edgerton 1963: 384). However, despite this initial interest in normality, Edgerton never went on to explicitly explore the concept of "normality" as a complex social and theoretical issue.
behaviour with meaning” (Edgerton 1984c: 503), Edgerton and MacAndrew argued 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 and MacAndrew (1970: 28) consequently disregarded the social and symbolic nature of other forms of behavioural expression and action. They ignored the means through which such people do communicate and engage with others, such as repetitive dispositional behaviour or the conscious utilisation of objects. In accordance with a symbolic scheme that identifies human sociality with language, reason and intelligence, such an interpretation relegated profoundly mentally retarded people to a status as "less human than some infra-human species" (MacAndrew & Edgerton 1970: 28; authors’ emphasis). Despite acknowledging a capacity for relationships, this interpretation denied profoundly mentally retarded people's capacity for a broader sociality.

Due to this interpretation, and because of his growing interest in the problems associated with deinstitutionalisation, Edgerton went on to exclude profoundly and severely retarded people from his anthropological analyses of the social and personal issues that deinstitutionalised mildly mentally retarded people have to contend with. He argued that severely retarded people cannot and do not exist in socially normal and acceptable circumstances and therefore were not suitable candidates for deinstitutionalisation. By extension, neither were they suitable for his study of the consequences of deinstitutionalisation. Those who were borderline retardates, and who had the capacity for "some intellectual tasks", were, Edgerton believed, capable of adhering to certain necessary social standards and conditions and were therefore worthy of social analysis (Edgerton 1967: 2-3).8 This concern with the life experiences of mildly

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8 Edgerton’s distinction between mild, moderate and severe mental retardation is sometimes confusing and contradictory. At times he argued that mildly
retarded people set the parameters for the sociocultural study of intellectual disability for over a decade. Not until David Goode's (1980a; 1980b) analysis of relationships between severely retarded children and their parents did the focus shift to picking up on Edgerton's earlier analysis of the possibility of social relations between severely retarded people and others.

**Edgerton's 'The Cloak of Competence'**

Edgerton's *The Cloak of Competence* was published in 1967 at a time when there was widespread criticism of the power of medicine, psychiatry, and the large mental institutions to interpret and control the lives of mentally ill and retarded individuals (for example see Goffman 1990 [1961], 1974 [1963]; Foucault 1995 [1961], 1986 [1963]; Laing 1960; Szasz 1977 [1961]). Due to this increasing social pressure, mildly retarded and mentally ill patients began to be released into the community, although there were concerns as to how they would fare and what factors should be taken into consideration when deciding who to deinstitutionalise. Edgerton spent the majority of 1960 and 1961 observing, interviewing, and analysing the lives of a group of mildly mentally retarded adults in order to gain some insight into these and other concerns. Most of his informants had been deinstitutionalised in 1954 from Pacific State Hospital—a large state hospital in California specifically for mental patients from which Edgerton drew the material for his earlier papers—and were now attempting to live as members of the general community. Through a series of formal but...
loosely structured interviews Edgerton sought to elicit from these people their experiences of being mildly mentally retarded. Using these interviews Edgerton built up life histories through which he formulated themes that were of concern for mildly retarded people living in the community. These included such issues as their relations with others, including sex, marriage and fertility; their neighbourhood, home and possessions; their self-perception, outlook on life, and employment, and what they did with their spare time (Edgerton 1967: 44).^9^ 

Theoretically, however, Edgerton was more concerned with how mildly retarded 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 understand the consequences of processes of institutionalisation, incompetence and labelling, and argued that deinstitutionalised mildly retarded people relied heavily on the support of non-retarded "benefactors" in order to successfully cope with life outside the institution (Edgerton 1967: 193). They also accumulated personal belongings to give the appearance of normality, made up biographies that denied their hospitalisation, or stated that, unlike the severely mentally retarded, they had been wrongly institutionalised and labelled as retarded. Despite this common denial of their retardation and institutional past, Edgerton argued that deinstitutionalised mildly retarded people still had to deal with the reality of being incompetent, and that it was this which most affected their life circumstances (Edgerton 1967; Luckin 1986: 94).

As a consequence of this assessment, Edgerton aimed to assess "the critical problems that these retarded people face in the management of their

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^9^ These issues, and the general theoretical concerns that Edgerton had with the consequences of labelling, stigma and dependency, were returned to by Edgerton in his follow-up studies of this same group of individuals (Edgerton & Bercovici 1976; Edgerton, Bollinger & Herr 1984).
incompetence” (Edgerton 1967: 142). Through analyses of their perceptions and experiences of life in the community, he argued that they utilised a "cloak of competence" to hide both the stigma of their discredited past as well as their inherent incompetencies (Edgerton 1967: 59-69, 143). Edgerton and Sabagh had earlier argued that attempts to pass as normal through "aggrandizement" were positive and necessary indicators of mentally retarded people’s capacity to live outside the institution (Edgerton & Sabagh 1962). Edgerton changed his interpretation in *The Cloak of Competence* and claimed that such attempts at passing and denial were in fact negative and indeed rather sad attempts at hiding the true and devastating nature of their retardation (Edgerton 1967; cf. Gerber 1990).

Not only were many of the people Edgerton studied dealing with the daily incompetencies of being illiterate and innumerate. They also found that being labelled retarded, and being associated with others who were even less competent than themselves, was the worst possible stigma they had to endure (Edgerton 1967: 146-149). 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).

They cannot accept themselves as mentally retarded and have self-esteem, Edgerton argued, because the stigma of retardation is total. Therefore to maintain self esteem mildly mentally retarded people must deny their retardation (Edgerton 1967: 207-212). Not only do they utilise a "cloak of competence" to pass as normal, but, as Goffman (1974 [1963]: 5) had also stated, they have to deal with the perception that as people with a demonstrable
stigma they were seen as "not quite human". This is a point that Jenkins (1998b: 19) has also made, although for him the focus is on competency rather than stigma and the association of cultural concepts of (in)competency with the constitution of the nature of normal humanness.

Edgerton argued that the stigma of mental retardation is expanded to subsume all possible competencies and that such people are "by definition, incompetent to manage any of [their] affairs [and are] forever doomed to [their] condition . . . There is no cure, no hope, no future. If you are once a retardate, you remain one always" (Edgerton 1967: 207). Mentally retarded people may seek ways to deal with this stigma, but they can never alleviate it entirely. Despite Edgerton's criticism of IQ scores (and other measurements of skills and competencies) as valid indicators of the potential success of social adjustment to the community—and his argument that age, personality, education, training, class and ethnicity are far better indicators of how an individual will fair after being deinstitutionalised (Edgerton 1967: 196-197)\(^\text{10}\)—the subjects of Edgerton's study were all, according to him, burdened by the stigma and reality of their low intelligence. Aside from seeing this as a consequence of both the clinical reality of retardation and the stigma of being labelled as such, Edgerton does not analyse why competencies associated with cognition and intelligence (in the narrowest of senses) have remained so central

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\(^{10}\) This concern with predicting the potential success of community adaptation is an issue that Edgerton takes up in his later studies. Edgerton and Bercovici (1976: 490) argued that the determining of what constitutes "successful community adaptation" is highly ambiguous and controversial, meaning as it does different things to different people, and especially to retarded people (a point that Edgerton takes up as one of the essential aims of research, ie. to discover what is meaningful for retarded people). The notion of successful community adaptation also has very complex, unspecifiable and multifaceted factors associated with it, and needs to be understood within a particular context and over long periods of time rather than being just a measure of skills, personality and competencies (Edgerton & Bercovici 1976: 489-495). Despite these concerns, however, quantitative assessments of social skills and competencies are still used in Australia as a means for determining the potential success of deinstitutionalising intellectually disabled people, as I discovered when I read my sister’s case notes.
to our perceptions of "normal" humanity. Neither does he explore why the stigma of retardation should be so 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.

Rather than analysing these issues, Edgerton argued that the solution to the problems associated with the stigmatised identity of mental retardation was to change the mental-medical-psychological aspects of the term into a behavioural one that does away with any reference to the stigma of low intelligence and incompetence (Edgerton 1967: 212). He suggests this for several reasons, all of them associated with improving the adaptation of mentally retarded people to life in the community. It is to encourage mentally retarded people to be "willing participants in their own improvement"; to make them more socially acceptable in their appearance and behaviour; more independent, productive, satisfied, and open to being educated (Edgerton 1967: 212-214; 1984c: 502). Ironically, despite Goffman's (1990 [1961]: 154-155) criticism of the pressure on mentally ill inmates to adopt the medical view of themselves as inherently ill, Edgerton is arguing that the acceptance of the "sick-role" is essential for successful community adaptation. As Séguin's treatments had done more than a century earlier, the process of community adaptation includes attempts to transform people who have been categorised as asocial and abnormal into normal and socially acceptable persons. The practice of training and management regimes in contemporary deinstitutionalised settings is an ongoing aspect of this.

Edgerton's Influence on the Study of Intellectual Disability

Through his use of Goffman's concept of stigma, in combination with Becker and Lemert's notions of labelling, Edgerton set the parameters of the debate

Those such as Douglas Raybeck (1988) argue that labelling is a process that is dependent on social types. Consequently, "large scale social units" have negative labelling effects due to decreasing interdependence and interpersonal information and increasing inequalities and formal mechanisms for treatment. This is the sort of process that Louis Rowitz outlines, whereby the label of retardation "becomes intertwined with the entire diagnostic process and with the approved interventions associated with that diagnosis" (Rowitz 1988: 1). Rowitz argues that the inclusion of mental retardation within the generic label of developmental disabilities has led to increased confusion and homogenisation in the areas of service provision (Rowitz 1988: 2). There are others, such as Marilyn Mardiros (1989), who claim that Mexican-American parents utilise the medical label of mental retardation in positive ways to gain access to essential services such as special education (a point which Rowitz
[1988: 2] also acknowledges as one of the positive effects of labelling). Charlotte Aull Davies and Richard Jenkins (1997), on the other hand, argue that incorporating the label "learning difficulties" into one's self identity is a complex process. To be properly understood it needs to be separated into discourses about learning difficulties and experiences of being disabled in this way. Despite these differences in opinion the focus on the impact of labelling and stigma has had far reaching consequences in the area of policy development and implementation. Through the influential work of Wolf Wolfensberger (1977), the negative consequences of being labelled mentally retarded and deviant were criticised and an alternative, known as the principle of normalisation, was instigated throughout the social services for intellectually disabled people in the USA, Europe and Australia.\(^\text{11}\)

Following in the footsteps of Edgerton, and associated with the Socio-Behavioural Research Group of the Mental Retardation Research Centre at UCLA, were those who advocated the life history approach to the study of mental retardation (Edgerton 1984b; Langness & Levine 1986). Rather than adhering to a "case history" approach that pathologises and objectifies those who are mentally retarded—and countering the overtly theoretical, quantitative, and technical accounts of mental retardation that exist in psychology and statistical sociology—researchers who adopt the life history approach use informal interviews to develop individual biographies that express the unique and diverse lived experience of being retarded (Gillman et al. 1997; Goodley 1996). Such accounts stress and acknowledge the subject's own interpretations and experiences of life (Easterday 1980: 221), and provide him or her with opportunities to articulate an authentic self-identity and voice (Atkinson & Walmsley 1999: 209; Booth & Booth 1996: 55).

\(^{11}\) Wolf Wolfensberger's theory of normalisation and the institutional practices associated with it is discussed in greater detail in chapter six.
In their different ways, researchers such as L. Langness, Robert Whitmore, Paul Koegel and Harold Levine have sought to portray what they termed an "emic" or "insider's version" of mental retardation.\footnote{Bogdan and Taylor (1982) were in fact the first to study mental retardation in this way.} Using life histories they focused particularly on issues of socialisation and incompetence and sought to portray the complex and dynamic interplay of these with environmental, social, familial, institutional and biological factors (Whittemore, Langness & Koegel 1986; Edgerton 1986). As Koegel, and Levine and Langness, point out, it is possible to be socialised into a state of incompetence through a labelling process that precipitates a loss of exposure to normal social experiences (Koegel 1986; Langness & Levine 1986; cf. Edgerton 1986). In this way, Langness and Levine argue, incompetence becomes a double bind. A person is not only perceived and labelled as inherently incompetent but becomes socially incompetent through their lack of social experiences (Langness & Levine 1986: 197).

This interest in the processes through which people are categorised as incompetent has continued to be a central feature of sociocultural studies of intellectual disability. Focusing on these processes through the lens of stigma and labelling theory, however, has often overshadowed an interest in the life experiences of intellectually disabled people from other perspectives. As well as this, incompetence has tended to be analysed as an individual experience rather than as a social phenomenon. In a recent collection of essays edited by Richard Jenkins (1998b) these theoretical concerns have been taken up and analysed from various perspectives. The notion of incompetence has been expanded to incorporate such issues as the effects of culture, economics and class on perceptions and constructions of competence and incompetence. The relationship of (in)competence to ideas of identity, personhood, sociality and normality has also been explored. And, as the form of the term...
“(in)competence” indicates, each of these more recent analyses acknowledges that any study of “incompetence” must inherently include within it the social and cultural notions of "competence" upon which it is based (Jenkins 1998b: 223).

The utilisation of narratives, life histories and auto/biographical based research with intellectually disabled people has also continued and proliferated in contemporary sociocultural studies of intellectual disability. These methods of research are used as tools for making visible the experiences of intellectually disabled people; people who are generally denied this opportunity because it is often believed that they have "no capacity for understanding or conveying their own situation or experiences" (Atkinson & Walmsley 1999: 209; cf. Easterday 1980: 217). Some, such as Danny Goodley (1996), stress the need for a critical reappraisal of the potential downfalls of this approach, particularly the assumption that social theory can be readily linked with an individual’s life history. Goodley (1996) is also critical of the potential to assimilate a person’s life story to the researcher’s own point of view (cf. Booth & Booth 1996: 63). However, the general assessment is that such research provides an important means for gaining access to the experiences of intellectually disabled people. As Tim and Wendy Booth argue, rather than interpreting the problems encountered with this style of research as a consequence of the person’s disabilities, narrative research should be developed in such a way as to include the stories of all of those who have difficulty articulating themselves (Booth & Booth 1996: 67).

Some of these life history and auto/biographical accounts of intellectually disabled people have been analysed in terms of the metaphors that such people develop to account for their life circumstances and experiences. Lois Easterday (1980) recounts the story of a young man who used military terms and adopted a military autobiography to account for his time in an institution. Reminiscent
of Goffman, Easterday (1980: 220) argues that this man substituted one total institution for another as a way of managing his spoiled and stigmatised identity. Although also analysing mental retardation within the parameters of stigma, Michael Angrosino (1992: 171-172) has sought instead to understand the "interactive communicative contexts" through which mentally retarded persons "create culturally appropriate metaphors by which to convey their sense of identity to others". Rather than focusing on the content of their life histories, Angrosino emphasises the "formal, stylistic properties of the narrative as the main conveyors of meaning" (Angrosino 1992: 173). He argues that the "metaphors of stigma" that mentally retarded people utilise help to produce meaningful and "shareable" accounts of their identity and selfhood (Angrosino 1992: 175-176; cf. Angrosino 1994; Angrosino 1998b).

Most sociocultural researchers in the field of intellectual disability have generally been concerned with analysing the consequences of social, welfare and educational policies. Just as Edgerton had done, they tend to focus on issues such as deinstitutionalisation and community adaptation (Begab & Richardson 1975; Heshusius 1981; Howard 1990; Johnson 1998; Langness & Levine 1986). Others have analysed the consequences of quality of life programmes (Atkins 1998; cf. Edgerton 1975) or special education practices (Blatt 1981; Gleason 1989). The aim is to improve the lives of intellectually disabled people by changing the way that these and other services are provided (Atkins 1998; Begab & Richardson 1975; Blatt 1981; Edgerton 1986; Gleason 1989, 1994; Goode 1984, 1990; Henschel 1972; Taylor & Bogdan 1989). Edgerton too went on to write many articles about mentally retarded people, constantly expanding and reworking his analyses and even criticising his own negative projections of the stigma associated with being labelled mentally retarded in follow-up studies with the people who provided the material for *The Cloak of Competence* in the 1960s (Edgerton & Bercovici 1976; Edgerton
Edgerton continued exploring issues of community adaptation, as well as taking on new social welfare concerns such as the implementation of normalization policies (Edgerton & Bercovici 1976: 485-6) and the problems associated with aging and providing a quality of life for the mentally retarded (Edgerton, Bollinger & Herr 1984). He also inspired others to study mental retardation from a cultural and social perspective, emphasising both the value of quantitative analyses and participant-observation, and the necessity of studying the perception and treatment of mental retardation in non-Western settings (Edgerton 1970, 1984a; cf. Manion & Bersani 1987).

Edgerton’s call for cross-cultural studies of retardation has been taken up by those such as Anne-Marie Henschel (1972), Joseph Westermeyer (1979), Larry Peters (1980), Marilyn Mardiros (1989), M. Miles (1992), Jeanne Connors and

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13 In these studies Edgerton discovered that the stigma of mental retardation had become less of an issue for these people, as had their reliance on benefactors (Edgerton & Bercovici 1976: 490-1; Edgerton, Bollinger & Herr 1984). Luckin comments that this decrease in stigmatisation was partly due to a shift in the social perception of those who were unemployed. He argues that this was a result of changing socioeconomic circumstances and increasing welfare dependency in the USA during the 1970s. As a consequence of this, ex-patients felt less “different” to many others in the community (Luckin 1986: 95).

14 Edgerton has written extensively about the importance of long-term participant-observation as a useful methodology for unobtrusively entering the lives of mentally retarded people and understanding their experiences and points of view within a specific context (Edgerton & Langness 1978; Edgerton 1984a; Edgerton 1984c). However, rather than just describing their lives and presenting a picture of the world from their perspective, Edgerton stressed that participant-observation also requires an objective detachment so that the researcher can analyse what these lives and experiences have to offer to a broader study of labelling, stigma, socialisation, institutionalisation, and personality development (Edgerton 1984c: 498). Such an approach, Edgerton argues, allows the researcher to analyse the underlying meanings and contradictions inherent in people’s expressions of self, exposing more fully who these people are rather than just what they think they are (Edgerton 1984c: 499). Although historically associated with anthropological studies of other cultures through the early fieldwork of Malinowski and Boas, participant-observation has more recently been taken up as a standard methodology in the other social and behavioural sciences. Many of the people whose work I discuss later in this chapter have utilised some form of participant-observation in their research.
Anne Donnellan (1993), Patrick Devlieger (1988), Mark Nuttall (1998), Susan Reynolds Whyte (1998), and Sylvia van Maastricht (1998). The general aim has been to understand the significance of intellectual disability within particular cultures (Mardiros 1989: 55), especially with regards to the "medical" issues of diagnosis, ætiology and treatment (Dentan 1967; Devlieger 1998; Miles 1992; Westermeyer 1979). Implicit within some of these studies is a critique of the dominance of the Western medical interpretation of intellectual disability, and the inappropriateness of Western models of treatment and policy development that are themselves based on cultural notions of independence and training (Maastricht 1998; Miles 1992: 249; Nuttall 1998; Whyte 1998). Others, such as Westermeyer (1979: 315), argue that similar interpretations of mental retardation over dispersed areas "suggests a common human experience with types of mental disorder, and a common need for understanding or explaining these disorders" (cf. Peters 1980). Despite the growing interest in intellectual disability from a cross-cultural perspective, it is still a relatively small field, as Connors and Donnellan (1993: 267) acknowledge; a reality that is perhaps indicative of some of the difficulties associated with studying people who do not readily play the role of informants.

An Uneasy Alliance: Intellectual disability and disability studies

At the time of Edgerton's groundbreaking sociocultural analysis of mental retardation the disability movement was also gaining momentum. This movement was comprised of a politically and socially motivated group of physically disabled people calling for self advocacy, equal rights, and equal access to services such as education, housing and transport, as well as employment (Barnes 1998: 68; Barton 1998: 58). Grass roots groups such as the Independent Living Movement in the USA and the Disablement Income Group
in the UK were pushing for radical changes to the way that disabled people were treated—socially, economically and politically—and challenging the barriers that segregated, oppressed, and excluded them from full participation in society (Barnes 1998: 69-70; de Jong 1982; Finkelstein 1998: 35-36).

Social theorists also began to argue that the problems associated with disability were as much a result of the social construction and experience of disability as it was a consequence of a physical condition (Barnes 1998: 69). These initial criticisms, although still steeped in what Colin Barnes (1998: 69) has termed a "rehabilitation role", marked the emergence of the social model of disability. Influenced by functionalism, symbolic interactionism, social constructionism and labelling theory in the USA, and by historical materialism in the UK, the social model of disability not only challenged the dominance of the medical interpretation of disability, but it also ultimately criticised medically informed sociological interpretations founded upon Parson's concept of the "sick role" (Barnes 1998: 66).

The existence of health and illness in society raised fundamental issues for Parsons, especially in relation to "the functional prerequisites of the social system" (Parsons 1970 [1951]: 430). Parsons’ functional interpretation of illness argued that sickness was a deviation from the functionally cohesive and socially prescribed norm of good health. The onset of illness potentially incapacitates people, preventing them from fulfilling their social obligations. The sick role provides a legitimate way of being in this temporary state. Illness thus becomes an alibi for incomplete sociality. However, this state is not without its own set of institutionalized obligatory practices. Those who experience illness must conform to the rules and demands of the sick role as a legitimate way of alleviating expectations to fulfil their normal social obligations (Parsons 1970 [1951]: 430-437). Parsons provides four obligations that must be adhered to by the patient if she or he is to be legitimately accredited the status of the sick role.
These include: "exemption from normal social role responsibilities"; accepting the passive role of being cared for by others; realising that this state is itself undesirable and that there is an obligation to "get well"; and seeking "technically competent help" in the form of a physician (Parsons 1970 [1951]: 436-7). Any threat to the cohesion of the social system is thereby alleviated through adherence to these socially and medically instituted practices, and a person can exist as a sick person so long as they accept these conditions (cf. Murphy 1990: 19; Conrad & Schneider 1985: 31).

Like the physically disabled that Robert Murphy (1990) wrote about, however, an intellectually disabled person may be categorised as medically unwell but they are not in a temporary state of sickness. Theirs is not a momentary deviation from normal obligations but a permanent state of being. Their status and social role as sick is therefore more complex than the illness that Parsons wrote of, although the same institutional relationships and obligations cross over into the clinical and institutional experiences of intellectually disabled people. Like the sick, they too become prisoners of the medical profession and must work towards their own rehabilitation in order to become accepted members of the community. They too are exempt from normal social responsibilities, must be cared for by others, are in an undesirable state that must be ameliorated or prevented, and are subject to the professional assistance of institutional and clinical staff. But as people who can never possibly transcend their difference, disabled people in general are forever trapped within the liminal and ambiguous state of being permanently damaged (Murphy 1990: 129-131). This is their abnormality.

The medical sciences, along with other medically informed sociological interpretations such as Parsons' sick role, argues Barnes (1998: 66-67), individualised disability. Medical science constituted the disabled person as the problem such that the individual experience of disablement was taken to be the
sole cause of any social or personal problems. By accepting this as natural fact, medical sociologists were seen to perpetuate this individually informed, pathologically based paradigm. Like disability theorists, Edgerton was also critical of the dominance of the medically informed literature within the field of mental retardation. However, his work—and the work of sociocultural theorists such as Langness, Levine, and Goode, who, along with Edgerton, were all associated with the Socio-Behavioural Research Group of the Mental Retardation Research Centre at the University of California, Los Angeles—cannot be readily incorporated within this social model of disability. Unlike disability theorists, and more in keeping with medical sociologists, they accepted the reality of retardation as a physical phenomenon. Rather than interpreting it as a social construction, Edgerton sought to determine the individual consequences of the stigma attached to being labelled retarded, and the difficulties that arose from living in the community with real incompetencies (Edgerton 1967).

In contrast, the social model of disability claims that disability is fundamentally a social rather than individual problem and it was in opposition to such medical interpretations that the social model evolved. Rather than analysing individual experiences, disability theorists sought to expose the social and systematic nature of disability (Abberley 1987; Oliver 1986, 1990). They consequently argue that the stigma, oppression, and deprivation associated with disability are a consequence of the social construction of disability as an abnormal deviance and/or the social relations and structures embedded in capitalist societies (Barnes 1998: 69; Barton 1998). As Anne Chappell puts it:

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15 I use the term "sociocultural theorists" to refer to those who study intellectual disability from a sociocultural perspective but do not adopt the social constructionist position advocated by those whom I have termed "disability theorists".

16 Included in this is the work of John Gleason (1989; 1994) which I discuss later in the chapter.
The analysis of disability presented by the social model is that disability is a social construct created by a range of historically and culturally specific factors. It is the social and economic structures of a particular society which create disability through processes of prejudice, exclusion and discrimination (Chappell 1998: 212).

The separation of the individual from the social, of the physical from the cultural, is signified in disability studies through the politically correct use of the terms "impairment" and "disability" respectively. While this allows for an analysis of the sociocultural, historical, political and economic aspects of disability, the sole focus on the social has meant that the personal experience and consequences of impairment have been seriously under-theorised. Only in the past few years have disability theorists begun to explore the meaning, embodied experience, and social consequences of impairment (Hughes & Paterson 1997; Meekosha 1998; G. Williams 1998). Rather than analysing it as a purely individual and personal phenomenon, however, those such as Gareth Williams have combined a materialist phenomenological approach with symbolic interactionism to explore the "interpretative process whereby individuals construct meaning from their experiences" (G. Williams 1998: 240; cf. Davis 1995; Hughes & Paterson 1997; Meekosha 1998). More recently there have been studies that have criticised this social/medical dichotomy, and argued that it is important to acknowledge that differences are both grounded in the body and subject to social interpretations (Atkins 1998: 7; Singer 1999).

The recent focus on the body, on the dis-abled body in opposition to "able-bodiedness", and on abnormality as a physical rather than intellectual construction, has problematic implications for those whose impairment is 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, and on physical and sensory rather than intellectual
impairments. 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.

Although there are obviously many important insights that the social model of disability has brought to the study of those who are disabled—such as the shift to focusing on the social structures that exclude disabled people and the sociocultural constructions that inform professional and social perceptions and treatments of those who are disabled—there are also some serious limitations to the social model. Even the analysis of impairment, while offering personal insights into the lived experience of disablement, in many ways perpetuates some of these problems. By constituting the medical model of disability as the primary cause of the problems associated with being disabled, disability scholars have denied the objective reality of intellectual, physical or sensory impairments. Consequently, they have ignored the social implications of differences that are undeniably embedded in the biological, and which constitute part of the experiences and identity of those who are disabled. Like labelling theory, it analyses the sociocultural experience of being disabled as a projection of social meanings and constructions. By incorporating intellectually disabled people within social analyses as "just like you and me", disability and labelling theorists have unwittingly denied to these people their real and actual differences. In the words of Robert Gordon, such an approach has fostered a "fundamental lack of respect for the meaning of real human differences" (Gordon 1975: 138).
Chapter Five: A Sociocultural Phenomenon

A Social Construction: The work of Bogdan and Taylor

The work of Robert Bogdan and Steven Taylor marked a significant shift in the interpretation and analysis of intellectual disability. Like Edgerton, Bogdan and Taylor emphasised the usefulness of qualitative research methods with intellectually disabled people (Taylor & Bogdan 1998). However, unlike Edgerton, they stressed the importance of phenomenology as a methodological tool. Bogdan and Taylor argue that the primary concern of the social scientist should be to understand "the social actor's frame of reference", the meanings they attach to things in their lives, and how these meanings influence the way that people act in the world (Taylor & Bogdan 1998: 3-7). Drawing on a combination of Mead's symbolic interactionism and Berger and Luckman's social constructionism, Bogdan and Taylor also argue that human behaviour and action is a product of how people define and interpret the world, and that the aim of social research is to understand how people construct their realities (Taylor & Bogdan 1998: 10).

Edgerton's work was criticised by Bogdan and Taylor for adhering to a medical interpretation of mental retardation (Bogdan & Taylor 1982: 208-214). While acknowledging the devastating impact of the stigma associated with being labelled mentally retarded, Bogdan and Taylor do not accept the argument that a part of this stigma is a result of being incompetent and retarded. In their book, Inside Out: The social experience of mental retardation, Bogdan and Taylor (1982: 5) argued instead that, rather than being an "objective condition", the entire meaning of the label of "mental retardation" is dependent on social and cultural concepts "that exists in the minds of people who attach that label to others" (cf. Taylor & Bogdan 1989: 23; Bogdan & Taylor
For them, mental retardation is fundamentally a social construction. As Bogdan and Taylor put it:

\[\ldots\text{the crucial issue in regard to the concept of mental retardation is not that some people (the poor, minority group members) are falsely labeled, or that the 'mildly retarded' are unfairly grouped with the severely or profoundly retarded. Rather, we dispute the efficacy and validity of the concept 'retarded' for any person, including those with the most profound organic neurological impairments (Bogdan & Taylor 1982: 5).}\]

Therefore, rather than telling us anything about the mentally retarded, the term "mental retardation" tells us about society and the methods by which people who do not fit the demands of industrialised society are perceived, categorised and administered (Bogdan & Taylor 1982: 9; Bogdan & Taylor 1976: 51). Through the application of treatments and services, and the experience of being institutionalised and stigmatised, Bogdan and Taylor argue that people labelled mentally retarded, rather than using a "cloak of competence" to hide the stigma of being retarded, have been covered with a "cloak of incompetence" that is impossible to discard (Bogdan & Taylor 1982: 222).

Through interviews with Ed and Pattie, two mildly retarded individuals who had experienced life in an institution but were now living in the community, Bogdan and Taylor (1982: 222) provide an account of the subjective, lived experience of mental retardation. Bogdan and Taylor acknowledged and empathised with Ed and Pattie as human beings with their own point of view. Their aim was to understand how Ed and Pattie constructed, thought and felt about the world and their place in it (Bogdan &

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17 For Robert Murphy, disability is a "social malady" that is defined by society and given meaning through culture (Murphy 1990: 4). It is a sociocultural rather than a biomedical phenomenon; a "metaphor of the human condition" and an "allegory of all life in society" (Murphy 1990: xi).
Taylor 1982: 20). In contrast to Edgerton, Bogdan and Taylor therefore became the first to fully acknowledge the integrity and lived experiences of mentally retarded people from their own perspectives (Gerber 1990: 4; cf. Bogdan & Taylor 1982: 4-18; Bogdan & Taylor 1976; Taylor 1998a).

David Gerber (1990) has argued that, by interpreting mentally retarded people as naturally and clinically retarded, Edgerton was unable to fully appreciate and respect these people’s own interpretations of their lives as anything other than attempts at dealing with the stigma of their retardation. Whenever they provided social reasons for their retardation it was interpreted as denial. Consequently, what they said about themselves was not taken at face-value. It was only ever a mask, and Edgerton, as the social analyst, was the one who could stand aside and interpret it as such. Therefore, argues Gerber, Edgerton failed in his attempt to understand the self-conceptions of mentally retarded people and subsequently denied them a valid voice (Gerber 1990: 5, 18). Rather than giving authoritative value to their experiences and interpretations, Edgerton reinterpreted, or rather subverted, mentally retarded people’s experiences and explanations, seeing these as proof of their inability to accept the reality of their circumstances (Gerber 1990: 10-15).18

In contrast, Bogdan and Taylor acknowledge the importance of the social context within which human variation is thought to exist, and claim that it is the way these differences are "thought about that matters" (Bogdan 1992: 316). However, they do not acknowledge or interpret the relevance of assertions of difference made by their informants when comparing themselves to those who

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18 Gerber recognises that it is unfair to retrospectively criticise Edgerton for not adhering to later interpretations of mental retardation as a social construction (Gerber 1990: 5-6), an interpretation which Gerber himself problematically accepts as true and unquestionable. Gerber acknowledges that Edgerton did, in some of his later articles, propose that cultural, social, economic and political systems could lead to different interpretations of retardation. However, Gerber also argues that Edgerton still fundamentally adhered to a clinical model, believing that a universal baseline level of competence could be discovered for all cultures (Gerber 1990: 6).
are severely mentally retarded. Although Bogdan and Taylor are keen to emphasise the similarities between mentally retarded and "normal" people, both Pattie and Ed—in much the same way as Edgerton’s (1967: 146-149) informants—had a deep disgust and fear of those who were profoundly retarded, and were offended by any association with them, categorically and in daily institutional life (Bogdan & Taylor 1982: 55, 133).

As well as this, Bogdan and Taylor—like Edgerton and those social theorists who adopted a life history approach to the study of intellectual disability—have primarily focused on the life experiences of those who are mildly mentally retarded. Despite arguing that all who are labelled retarded are subject to the social construction of them as such, in most of Bogdan and Taylor's work the social experiences of severely retarded people have not been analysed. The reliance on interviews and the recording of life stories is often inappropriate for those who have more limited forms of communication. Also, while being labelled intellectually disabled has serious social consequences for all who are caught up in the clinical and institutionalised system of services, it is not always expressed as a personal concern for those who are more severely affected.

The tendency to focus on the social experiences of those who are categorised as mildly retarded circumvents the problems encountered when analysing the lives of those who are more severely and obviously affected by their disability. While social, cultural, historical and material factors have a profound affect on the lives of all those who are labelled intellectually disabled, they 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 a product of sociocultural constructions and structures, tend to deny that intellectual disability is an ontological reality that makes a real difference to the experience of being intellectually disabled. Consequently, Bogdan and Taylor are unable to deal
with the real implications of difference as productive of the sociocultural world rather than just the products of it.

Bogdan and Taylor have recently criticised their own earlier work for adhering to a "sociology of exclusion" by only emphasising the consequences of stigma, deviance, labelling and stereotyping (Bogdan & Taylor 1998: 242-243). They now acknowledge that there are a variety of ways in which mentally retarded people are perceived, and that a significant number of social relationships with such people emphasise acceptance rather than exclusion. Through familial relationships, religious convictions, humanitarian concerns and/or friendship, they argue, it is also possible for retarded persons to be positively perceived and treated. Consequently, in such circumstances, mentally retarded people's disabilities do not have a stigmatising or "morally discrediting" effect (Taylor & Bogdan 1989: 27). Bogdan and Taylor call for a "sociology of acceptance" as a way of understanding this phenomenon, arguing that such intimate and accepting relationships are important in mentally retarded people's lives (Taylor & Bogdan 1989: 22; cf. Bogdan 1992). As they put it:

. . . the definition of a person is not determined by either the characterisation of the person or the abstract social or cultural meanings attached to the group of which the person is a part, but rather by the nature of the relationship between the definer and the defined (Bogdan & Taylor 1998: 243).

Despite this emphasis on relationships, the constructionist approach that Bogdan and Taylor adopt still focuses on differences in the definition and social meaning of those who are retarded. It explores how these definitions determine the way that such people are subsequently treated and perceived. Difference for Bogdan and Taylor, although not denied, is primarily a
consequence of social definition and categorisation, and what is important is the meaning attributed to difference through the perspectives of those who are not disabled (Bogdan & Taylor 1998: 245). Consequently, Bogdan and Taylor’s interpretation of mental retardation remains thoroughly within the rubric of symbolic interactionism and social constructionism. Their particular approach has also perpetuated and reinforced Edgerton’s earlier dismissal of anthropological theories of culture and symbolic representation as relevant for interpreting the sociocultural experiences of intellectually disabled people. This has meant that intellectually disabled people have been interpreted as social beings only in so far as they are products of the labels attributed to them. While we gain a sense of severely intellectually disabled people as human beings whose humanness is a product of social relations with others, we do not gain a sense of the meanings that they themselves create, nor of them as the authors or independent sustainers of mutuality and sociality.

An emphasis on the social definition of, or meanings attributed to, intellectual disability became increasingly prominent in the work of those who took up Bogdan and Taylor’s social constructionist paradigm. This includes cross-cultural studies of intellectual disability, analyses of representations of intellectual disability in the media, as well as post-structural and deconstructionist accounts of the concept of intellectual disability. Rather than interpreting intellectual disability as an ontological state of being, the tendency in these cases is to use the variability of cultural and historical concepts of "mental retardation" as proof of its inherent emptiness as a concept (Manion & Bersani 1987; cf. Connors & Donnellan 1993). In such analyses the focus tends to shift towards a concern with categories, constructs and labels, as well as to social institutions and structures, and how these impact upon the interpretation of intellectual disability. Rarely does it enter into intellectually disabled people’s lives as ones which are more, or other, than just the consequences of these
supposedly overarching and deterministic constructs. In such accounts it is impossible to get a glimpse of who intellectually disabled people actually are, how they relate to and engage with others, and what sort of meaningful worlds they inhabit and produce.

Analyses of images and representations of intellectual (and other) disabilities in film, literature and the media by Paul Longmore (1985), Alan Gartner (1982) and Robert Bogden et al. (1982) ignore the inherent sociality of intellectually disabled people, implying that their experiences are entirely the product of such stereotyping. The same can be said for more contemporary analyses of intellectual disability that employ post-structural, postmodern and/or deconstructionist methodologies. 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 more fully 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 those very constructions that supposedly constrain them (Branson & Miller 1989; Ellis 1998).

Many contemporary researchers who explore cross-cultural conceptions of intellectual disability also tend to focus solely on the social and cultural categories and meanings associated with intellectual disability. Describing their research with the Navajo, Connors and Donnellan stated that:

The diagnoses of the individuals in this study included severely multiply handicapped, severely mentally retarded, autistic, Down’s Syndrome, and educationally mentally retarded. All were non-verbal and unable to express their own experiences; thus, data were gathered from families, neighbors, caretakers, and others
directly involved with these individuals as to how they were regarded in the Navajo world view, to what extent the individual was considered a competent member of the culture, how the behaviour associated with the disabilities as [sic] dealt with, and how problematic this might be (Connors & Donnellan 1993: 269).

Connors and Donnellan's study provides valuable information on some of the sociocultural and historical differences in the perception, treatment and interpretation of those who are regarded as intellectually disabled. It also acknowledges that institutional practices exist within a specific sociocultural context. However, Connors and Donnellan also deny or disregard three very important issues. One is that the researcher, and the culture in question, must recognise the differences they are observing as some form of intellectual disability in order to study them as such—an issue that, as Jenkins (1998b: 4) points out, raises epistemological problems concerning the use of "intellectual disability" as an analytical category at all. Secondly, it is assumed that being intellectually disabled, these people are therefore "unable to express their own experiences". And thirdly, that cultural constructions are the most significant and theoretically meaningful aspect of a social analysis of intellectual disability.

Unwittingly, such analyses perpetuate the clinical interpretation of intellectual disability by ignoring the fundamental sociality of intellectually disabled people. We tend to learn more about what they signify and represent as objects of sociocultural construction rather than who they are as subjects engaging in relationships with others. They may be products of cultural categories but are not analysed as active participants in social life. They may experience what it is to be labelled retarded but are not theorised as people interacting with others as part of the mutual sociality of everyday life. This denies to intellectually disabled people a status as encultured beings, who,
although limited in their ways of participating in the social world, do seek ways of meaningfully and socially engaging with others.

**Intimacy and Relatedness: The work of Goode and Gleason**

While also drawing on the methodological principles of participant-observation and qualitative analysis, the work of David Goode and John Gleason has provided us with a different and, I would argue, potentially more significant insight into the lives of intellectually disabled people. Rather than focusing solely on the stigma of labelling or the social construction of retardation, both Goode's and Gleason's work therefore represents at least a partial break with the first two "schools" of sociocultural analysis. Instead, Goode emphasises the centrality of intimacy and familiarity in the construction of a positive identity for intellectually disabled people, while both he and Gleason have made the intentional and purposeful interactions of people with severe and profound multiple disabilities the subject of their, albeit slightly different, analyses. While intimacy and relatedness may have been implied as attributes of the social lives of those with mild intellectual disabilities, they had never been the focus of analysis. Nor had they been emphasised in relationships with, and between, those who are severely intellectually disabled.\(^{19}\)

The first person to discuss intimacy and relatedness in relation to intellectually disabled people was David Goode.\(^{20}\) Employing a combination of ethnomethodological and phenomenological techniques, Goode sought to enter the everyday world of multiply impaired children in an attempt to

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\(^{19}\) An exception to this is Edgerton's early paper with MacAndrew on the possibility of friendship between two severely retarded individuals (MacAndrew & Edgerton 1966).

\(^{20}\) Interestingly, David Goode was trained in ethnomethodology at UCLA by two of Edgerton's colleagues, Harold Garfinkel and Melvin Pollner. Goode was also led to his research subjects by Edgerton (Taylor & Bogdan 1998: 123).
discover the grounds for their intersubjectivity (Goode 1980a; 1980b; 1990). Rather than interpreting their behaviour and interactions according to the sorts of "'scientifically' produced standards of 'normality'" that clinicians utilise, Goode emphasised the importance of "naturalistic" contextual data gained through the observation of interactions in everyday life (Goode 1980a: 97). As Goode put it, such clinical interpretations are:

. . . 'specifically indifferent' to the familial context of action. They decompose meaningful familial interaction into clinically locatable problems with regard to—in fact sometimes in direct contradiction with—the lived realities of everyday family life (Goode 1980a: 97).

Goode's earliest work drew upon his interactions with a congenitally deaf-blind and retarded girl called Chris who lived in a state hospital ward. Rather than interpreting Chris' behaviour as meaningless, faulty, and in need of remedial training—as the staff did, and which he too initially attempted to do—Goode sought to understand it on its own terms (Goode 1980b: 193-198). Recognising that Chris lived in a significantly different perceptual/cognitive world to his own due to her disabilities, Goode decided that "only intimate and persistent interactional contact . . . would be likely to enable [him] to enter [her] world" (Goode 1980b: 187-188). Consequently, Goode developed "interactional strategies" which included mimicking Chris' repetitive behaviour and her perceptual, tactile engagement with the world in order to build up a basis for intersubjectivity on Chris' terms.

Goode discovered that Chris responded enthusiastically to sound stimulation, especially to the rhythm and frequency of music, as well as to touch. She used her tongue for sensory gratification and to gain information about objects in her world. As well as these, Chris exhibited "autostimulatory behaviours" such as finger flicking, rocking and head swinging in response to
light and sound, although as Goode points out, the use of her senses was also goal-oriented (Goode 1980b: 189-190). Chris also loved physical interaction, and although she did not recognise or utilise linguistic symbols, Goode argues that through her sensory interaction with the world and others, she did communicate (Goode 1980b: 191). Chris used gestures, gross physical movement and "background expectancies", such as sitting at a table in the dining room to express her hunger, to communicate her needs and desires to others (Goode 1980b: 191-192).

Chris' difficulties stemmed from her lack of audiovisual perceptual abilities, upon which, Goode argues, "we build our systems of symbolic communication and organize our practical interactional activities" (Goode 1980b: 192). However, through long term and intimate observations of her behaviour and interactions Goode was able to gain an appreciation of Chris’ abilities, and perceive the rationale, intelligence, inventiveness and purpose in her actions (Goode 1980b: 197-201). Goode argues that we all live in an intersubjective and shared world. Drawing on Schutz’s epistemological queries as to the possibilities and nature of this shared world, Goode states that "we progressively developed common schemes of communication, congruent practical relevancies, mutually defined things to do in the world, and so forth" (Goode 1980b: 204-205). Through entering Chris’ world on her own terms, Goode sought to establish such "common schemes of communication".

Although at first Goode attempted to simulate Chris’ deafness and blindness, he realised that he needed to let Chris direct their interactions in order to gain insight into what the world meant to her (Goode 1980b: 193-195). This involved allowing Chris to play with him in such a way that she gained sensory gratification from their interactions. It included such things as having Goode rhythmically tap her ears, play music, swing Chris on his knee and rock her. Through these interactions, and through mimicking Chris’ actions, Goode
recognised that there was an inherent purpose and rationale to Chris' behaviour. There was a definite pattern to Chris' actions through which she sought rhythmic sensory stimulation and gratification (Goode 1980b: 197-199).

Goode’s interactional encounters with Chris were ground-breaking for the sociocultural study of intellectual disability. They represented the first written sociocultural analysis of a severely intellectually and physically disabled person’s world. In doing so, Goode recognised that it was possible to find intention and meaning in such a world. Rather than embodying culture in linguistic capabilities and recognisable cultural enterprises, Goode acknowledged that it was possible to develop a sense of a shared world through purposeful and intimate interactions (Goode 1980b: 203-205).

Goode’s interest in the possibility of developing communication and a meaningfully shared and intimate world was elaborated upon in his analysis of the communication system that existed between an ailingual deaf-blind and retarded child (Breta) and her family (Goode 1980a; 1990). His primary concern in this situation was with whether or not such a "communicational relationship" should be considered abnormal or extraordinary (Goode 1990: 29). Drawing again on Schutz, Goode argued that all communication is, to a degree, partial, incomplete and incoherent. While this may be intensified in relationships with severely intellectually disabled people, in essence it represents the same form of communication that we all utilise (Goode 1990: 29-30).

The ways in which behaviour and gestures are interpreted, such as inferring knowledge based on prior experience, supplying props and leading questions, and filling in the gaps which exist in relationships, has been interpreted by Goode as "behavioural sculpting" (Goode 1980a: 101). He argues that in the relationship between Breta and her mother the intention of this "sculpting" was not entirely for the benefit of outsiders, but that it existed in order to
"normalize' the look and feel of the family for themselves" (Goode 1980a: 101-102; author's emphasis). It was a way of including Breta in the ongoing dynamic interactions of the family, not in conformity to expected norms of behaviour, but in terms of how her behaviour was being interpreted by those in intimate daily contact with her.

Goode incorporated severely intellectually disabled people within his social analyses, and stressed such people's involvement in the wider social world through intersubjectivity, interaction and intimacy. In his work with Chris, Goode was the one to develop and engage in the necessary interactional strategies for intersubjectivity. He used observations of these intimate interactions as source material for his analysis (Goode 1980b). In his research with Breta, Goode utilised the perspectives and interactions of an (intimate) outsider (Goode 1980a; 1984). As Goode himself acknowledged, he gained access to Breta via her mother's "intimate gossed knowledge" and not through his own interactions (Goode 1980a: 111).

While Goode's primary interest has been to analyse the possibility of communication and intersubjectivity between severely physically and mentally retarded people and others, he has become best known for his contribution to social constructionism. In a similar vein to Taylor and Bogdan's (1989) more recent emphasis on a "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 with profoundly physically and mentally retarded persons and clinical, objective perceptions that interpret such people as negative and entirely deficient, subhuman beings (Goode 1984: 229). Drawing on a number of examples of different types of relationships, including his observations of Breta's relationship with her mother, Goode argued that familiarity and
intimacy are the necessary factors for perceiving recognisable human attributes and competencies in a severely retarded person (Goode 1984: 244-245).

Although intimacy may change the subsequent 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 Goode emphasises. As Goode elaborates, the idea of a socially produced identity:

... refers to how a person’s identity—who he or she is taken to be in terms of the significance or meaning attached to his or her body and behaviours—emerges out of a concrete and particular social situation and is the product of social interaction with that situation (Goode 1984: 231).

Despite his argument that communication implies far more than linguistic competency, Goode later stipulated that the persons he studied "do not use symbolic language" (Goode 1990: 30). Therefore, although he focused on the possibility of intersubjectivity and communication, Goode went on to emphasise differences in the social perception of intellectually disabled people rather than analysing the symbolic systems that are developed and mediated through the course of mutual interaction.21

21 Chris Atkins (1998) has taken up the issue of intimacy that arose out of the work of Goode and Bogdan and Taylor and applied it to an analysis of quality of life policies. Rather than emphasising access to services, lifestyle, integration and deinstitutionalisation as the necessary components for an improved quality of life for people with severe multiple impairments, Atkins argues that such people’s quality of life, and indeed their very identity and "situated belonging", depends on the interactions that they have with significant others (Atkins 1998: 7-8, 241). The intimate support through "just little things" that carers provide for people with severe multiple impairments allows them to just be (human), and to be accepted (Atkins 1998: 263). Atkins claims that contemporary practices in the field of intellectual disabilities have the potentially devastating effect of isolating people in a world where they do not become known and where the meaningful things in their lives are never perceived (Atkins 1998: 238-9). As she comments: "Removal of nurses who have become intimate with people with severe multiple impairments means that their definition of quality of life
John Gleason (1989; 1994), on the other hand, has pursued a course of analysis that focuses on such issues through observing the meanings and intentions that exist in severely multiply disabled people's interactions with one another. Gleason argues that the way these people 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; cf. Gleason 1994; Goode 1980b: 192-193; Lea 1988; S. Taylor 1998b: 198-199). Gleason claims that this clinical interpretation of behaviour is the result of a profound disturbance in disabled people's physical form and function. This has meant that everything such people do, that all their actions and interactions, have been observed and interpreted in the light of their disabilities and deficits (Gleason 1994: 256-257). This subsequently denies to severely disabled people the possibility of having their own already unique modes of meaningful interaction within the specificities of their disabilities (Gleason 1994: 248).

With an interest in analysing the consequence of therapeutic and special education practices—which included changes brought about by deinstitutionalisation and normalisation policies—Gleason spent five years observing the interactions of a group of residents at a state school for physically and mentally retarded people. The emphasis in special education, collapses for, without intimate interaction, there cannot be individualised support for humans being" (Atkins 1998: 239; the term "humans being" is drawn form the work of Draper and acknowledges that we are all human social beings who engage with one another and the social world via our individual identities, our bodies and emotions). This same concern was raised in the work of Goode (1984: 246) and Taylor and Bogdan (1989: 33-34). It also resonates with some of Gleason's arguments concerning the problems inherent in contemporary special education practices, although his approach marks a significant departure from these other interpretations. In a very different way, and drawing her theoretical orientations from postmodernism and deconstruction rather than interactionism and phenomenology, Elisabeth Ellis (1998) has explored the "spatial politics of disablement" that separates non-disabled from disabled people. Rather than adhering to what she interprets as modernist and dichotomous modes of oppositional identity upon which this separation is based, Ellis calls for an inclusive ideology based on "webs of nurturance" which she identifies as familial proximity and connectedness (Ellis 1998).

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from Séguin's early treatments right up to the present day, has been to instil in intellectually disabled people more conventional modes of communication and interaction. This has meant that staff tend to see and interpret the behaviour of residents in terms of the conventional and dominant clinical and pathological view of mental retardation. It has also meant that they only see as meaningful and cultural those actions that conform to normative behaviour. While severe and profound disabilities may set limits to the possibilities for communication and interaction, Gleason argued that it does not inherently define what such people do. Nor does it determine the quality of their actions and interactions (Gleason 1989: 10).

Gleason (1994: 260) argues that the implicit meaning and intention in severely multiply disabled people's interactions can be observed if it is acknowledged that what they are doing conforms to a recognisable pattern and has relevance and meaning for them. By maintaining a sense of the context within which these actions and interactions take place Gleason was able to observe the intentional patterns in these people's behaviours towards one another. By adopting a methodology that interpreted the relationship between form and function in the production of meaningful content—rather than focusing on the disturbances caused by a disruption to form and function—Gleason acknowledged that such actions and interactions are meaningful (Gleason 1994: 247-249; Gleason 1989: 79, 106, 152). He consequently sought to understand what the behaviour and interactions amongst the residents might mean to them (Gleason 1989: 2).

The contributions of Goode and Gleason to the sociocultural field of intellectual disability are highly significant and important. In their different ways both incorporated severely intellectually disabled people into the social world that was under analysis. Goode emphasised the importance of intimacy and relatedness, while both he and Gleason acknowledged the meaning and
intention in severely disabled people's actions and interactions with others. The analyses of Goode and Gleason have many resonances with my own research with intellectually disabled people. So does the discrepancy between their own and staff observations and interpretations, the latter of which were based on historically and clinically mediated perceptions. While I also emphasise these issues, I utilise different theoretical tools to interpret the fundamental sociality and symbolic intentionality of intellectually disabled people's actions and interactions. Like Goode, I emphasise the role that intimacy and relatedness play in the recognition of severely intellectually disabled people's sociality. In doing so, however, it is important to emphasise just what is meant by intimacy, and to distinguish my own use of the term from how it has been used by others.

Goode used the concept of intimacy to highlight the nature of long-term, empathetic relationships that people can have with those who are severely intellectually disabled (Goode 1984). Through intimacy, Goode argued, a positive social identity can be developed that emphasises the humanness and competencies of the disabled person. Intimacy in this sense allows for the production of a positive social identity. Intimacy also implies acceptance (Bogdan and Taylor 1989), or, as Atkins has put it, "assisted belonging" (Atkins 1998). The purpose of intimacy in these analyses is to highlight differences in the ways that severely intellectually disabled people are perceived and related to, especially in comparison to clinical interpretations. While I accept that these are aspects of intimacy, I argue that it is through what Schneider (1968: 52) has termed an "enduring, diffuse solidarity" that intimacy exists. Intimacy, therefore, is not just about acceptance of another, nor is it solely the necessary factor in the production of positive social identities. Intimacy emerges through mutuality, which itself exists as the fundamental ground of sociality.
Drawing on Wittgenstein's (1998 [1953]) notion of language games, and Geertz's (1993b [1973]) concept of culture, I argue that meaning is public and that it exists in the use to which words and objects are put. Behaviour in this sense becomes symbolic, interpretable and meaningful; patterned dispositions to act and interact in certain ways. Through intimacy, mutuality and relatedness these symbolic systems and dispositions are recognised and engaged with. Such symbolic practices contribute to the form of life or sociality that is consequently created through such engagements. Intimate encounters with intellectually disabled people allow for an awareness of their particular symbolic practices and dispositions. The tragedy is that few people in intellectually disabled people's lives have the aspiration to generate a sociality and mutuality based on intimacy. Clinical interpretations tend to deny or disregard that such forms of sociality and mutuality are even possible and relevant. The practices of training and management that have been instituted on the basis of these interpretations have subsequently had a profoundly dominant and disturbing effect on intellectually disabled people's life experiences.