Denying Intimacy:
The Role of Reason and Institutional Order in the Lives of
People with an Intellectual Disability

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List of Persons

Siblings

Joseph (b. 4/5/1958)
Stephen (b. 11/7/1960)
Maryla (b. 10/11/1961)
Ursula (b. 1/10/1963)
Jani (b. 17/9/1965)
Tessa (b. 16/3/1968)
Peter (b. 29/6/1970)

Intellectually Disabled People at "Xanadu" (and place of residence)*
* all names of people and places associated with my fieldwork have been changed to protect their privacy

Cressida (Jeffrey Street)        Martin (Home)
Daniel (Home)                  Patricia (Jeffrey Street)
Jacky (Corrie Street)          Polly (Jeffrey Street)
Joanne (Jeffrey Street)        Rachel (Home)
Kate (Corrie Street)            Sarah (Jeffrey Street)
Mary (Hervey Street)            Tony (Jeffrey Street)

Other Intellectually Disabled Persons Mentioned (and place of residence)

Jane (Jeffrey Street)           Colin (Hervey Street)
Jill (Jeffrey Street)           Jim (Hervey Street)
Kerry (Jeffrey Street)          Sally (Hervey Street)
                              Shauna (Hervey Street)
**Glossary of Terms and Places**

DOCS - Department of Community Services


ISPs - Individual Service Plans

IQ - Intelligence Quotient

MA - Mental Age

NSW - New South Wales

Grosvenor Diagnostic Centre - Formerly known as the Grosvenor Mental Deficiency Diagnostic Centre. Now known as the Department of Community Services Disability Specialist Unit.

Stockton Hospital - Now known as the Stockton Centre for Developmentally Disabled People.

"Corrie Street" - DOCS Community Group Home

"Huxley Street" - DOCS Community Group Home

"Jeffrey Street" - DOCS Community Group Home

"Keynton" - Paper Shredding Unit attached to Xanadu

"Xanadu" - Activities Centre
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For Stephen, Maryla and Ursula
Denying Intimacy:
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Jani Klotz

Abstract

This thesis explores differences in the ways that intellectually disabled people are perceived, interpreted and related to within a Western context. Through a comparison of familial and institutionalised forms of relatedness, it examines the interrelation between these differences and the consequences that they have for either denying or acknowledging severely intellectually disabled people’s capacities for sociality. Drawing on Carrithers’ (1992) concept of sociality and mutuality, and Wittgenstein's (1953) notion of language games, the thesis analyses the means by which a meaningful and shared existence with intellectually disabled people can be negotiated and developed. Although limited and restricted in their capacities for symbolic expression, such people do have modalities of symbolic life upon which sociality can be built. By analysing the symbolic practices utilised by my three profoundly intellectually disabled siblings, I seek to show how relationships across the difference of intellectual disability are able to be symbolically mediated and negotiated. I argue that it is necessary to engage in relations of mutual interdependence in order to even recognise and perceive these practices as purposeful and meaningful. The mutuality that ensues requires a level of intimacy, empathy and commitment that is not easily sustainable, but which is necessary for the maintenance of intellectually disabled people's existence as social beings.

These intimate relations are contrasted with clinical and institutional forms of relatedness, both of which have been informed and shaped by a symbolic scheme of
reason and normality. This symbolic scheme associates a capacity for reason with normal humanness, where reason is identified as particular abstract, linguistic, mental practices that are then deemed necessary for sociality. These are what intelligence tests measure, and it is through such assessments that intellectually disabled people are rendered asocial. The pathologising of intellectual disability as an abnormal embodiment, and the clinical tendency to search only for deficits in functioning and ability, has led to a denial or ignorance of intellectually disabled people’s abilities to be the independent sustainers and authors of mutuality and sociality. I draw on my family’s medical notes, records from the institution where two of my siblings were sent to live, as well as observations made during twelve months of fieldwork with a group of intellectually disabled people attending an activities centre, and either living in community group homes or with their families, to elucidate the ways in which such interpretations of intellectual disability become instituted into daily practice.

The instituting of training and management practices within day centres, group homes and institutions for the intellectually disabled are a consequence of the perception that intellectually disabled people have no capacity for sociality as they are. So too are the legal and structural obligations that inform the forms of relatedness that staff have with the intellectually disabled people with whom they work. These relations are based on separation and disengagement rather than mutuality and intimacy. The aim in these institutionalised environments is to instil in such people a range of normative social, domestic and vocational skills as though it is upon these that their capacity as social beings are dependent. As a result, the symbolic practices and dispositional behaviours through which intellectually disabled people express themselves are not recognised as such, nor are they engaged with. This undermines intellectually disabled people’s capacity to be joint contributors to social life in a way which incorporates their differences rather than trying to transform them.
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Introduction

How is it that forms of sociality are generated and sustained with people who have severe and profound intellectual disabilities? And why is it that such people’s capacities to create and engage in meaningful relations with others are so readily denied or ignored? These are two of the central questions that have motivated this thesis, and provide the underlying themes of the following seven chapters. Although limited and restricted in their capacities for symbolic expression, intellectually disabled people do have modalities of symbolic life upon which forms of sociality and mutuality can be built. Through an analysis of the symbolic practices and dispositional behaviours utilised by my three intellectually disabled siblings, I show how relationships across the difference of intellectual disability are able to be symbolically mediated and negotiated. I argue that it is necessary to engage in relations of mutual interdependence in order to even recognise and perceive these practices as purposeful and meaningful. The mutuality that ensues requires a level of intimacy, empathy and commitment that is not easily sustainable, but which is necessary for intellectually disabled people to exist as social beings as they are.

I juxtapose this social and symbolic milieu with that of an institutional life devoted to the normalisation, management and training of intellectually disabled people. These institutional environments include government-funded community activities centres, sheltered workshops, group homes, and large-scale institutions. In such environments, intellectually disabled people are trained to develop particular social skills deemed necessary for sociality. These include domestic and vocational skills, as well as specific communicational skills through which people are expected to express themselves and engage with one another. Such institutional practices have been informed by clinical
interpretations of intellectually disabled people as abnormal and deficient, asocial beings. They disregard the fact that what makes us persons, and allows for a multiplicity of persons, is our human capacity for mutuality and sociality, as well as our creative potential to produce different symbolic systems through which we engage, communicate and make meaningful the world to one another.

Despite a growing interest in the social experiences and perceptions of intellectually disabled people, the study of intellectual disability remains a relatively small field within the social sciences. Moreover, most of the sociocultural research that has been done has tended to focus on the social experiences of people with mild rather than severe or profound intellectual disabilities (Edgerton 1967; Bogdan & Taylor 1982). This is partly a consequence of the difficulties involved in using people who are severely intellectually disabled as informants. However, it is also a product of the perception that such people lack the capacity for symbolic expression. This view underpins clinical perceptions (Kanner 1944; Wing 1996) as much as it informs some sociocultural accounts of people with intellectual disabilities (MacAndrew & Edgerton 1970). The association of symbolic representation and expression with specific intellectual and linguistic competencies, and the notion that these are a necessary condition for cultural behaviour, has allotted those who lack such skills a place outside, or at best on the borders of, human encultured sociality. This thesis therefore involves a critique of the implicit or explicit denials of intellectually disabled people's capacities for sociality in a range of written studies and social environments, including historical documents, clinical and institutional records, and familial and institutional milieu.

In chapter one I provide a description of the forms of sociality and symbolic expression that my three intellectually disabled siblings created and utilised in their everyday lives within the intimate domain of our family life. Through an
analysis of their particular, highly contextualised and often embodied, symbolic and dispositional practices, I show how my siblings were capable of producing and sustaining mutual and intimate relations with one another and their non-intellectually disabled kin. Drawing on Carrithers’ (1992) concepts of sociality and mutuality, Bernstein’s restricted codes (1971; 1977), Geertz’s (1993a [1973]) interpretation of culture, and Wittgenstein’s (1998 [1953]) notion of language games, I analyse the means by which a meaningful and shared existence across the difference of intellectual disability is able to be developed and maintained. I show how my siblings’ symbolic and dispositional practices were incorporated into and helped define my family’s specific form of life, and how my siblings’ existence as social beings ultimately depended upon levels of intimacy and interdependence that were generated within these familial relationships.

In chapter two, I explore some of the consequences of disrupting this familial intimacy. I examine the impact of social attitudes towards intellectually disabled people in general, and explore how these came to affect the ways in which I and my non-intellectually disabled siblings dealt with the stigma of having intellectually disabled kin. The chapter also includes an account of the tensions, difficulties and differences that were created when the intimacy of the home environment was replaced with the anonymity of institutionalised and clinical settings. In the second section of chapter two, I introduce my fieldwork, which was done with a group of intellectually disabled adults living in "the community" in government-funded group homes and attending an activities centre or sheltered workshop. I outline the forms of relatedness that exist within these "institutionalised" environments, and show how, despite recent changes in policies towards intellectually disabled people, these relationships are moulded and constrained by legal and institutional structures and obligations that continue to undermine intellectually disabled people’s capacities to represent and express themselves as social beings.
Having introduced my two main "ethnographic sites", I then turn to analyse why it is that intellectually disabled people are perceived, interpreted and treated as asocial and abnormal beings within both clinical and institutional environments. I argue that the written documents that constitute the literature on intellectual disability—which includes historical, philosophical, religious, medical, psychological, welfare, educational and institutional records—embody shared and implicit assumptions about the nature of human nature. These can readily be interpreted as constituting a "symbolic scheme of reason and normality", where a "symbolic scheme" represents the taken-for granted ideas and values to which a cultural milieu conforms (Sahlins 1976). It is this scheme that orders and informs clinical interpretations of intellectual disability. It also informs the practices of training and management that have become the dominant modes of engaging with intellectually disabled people in institutionalised environments. Rather than merely being descriptions of intellectual disability, such material is also constitutive of the environments within which intellectually disabled people exist. As part of the discourse of reason and normality I have therefore incorporated what would normally be material for a literature review into my analysis of the ways in which intellectually disabled people are perceived, interpreted and treated. Throughout the thesis I make links between this material and my ethnographic notes and siblings' clinical records in order to describe and analyse the inter-related discursive forms drawn together by a symbolic scheme.

In chapter three I analyse the role that notions of normality play in this symbolic scheme by looking at the history of medical interpretations of intellectual disability. I explore the shift from religious interpretations of intellectual disability as a mark of sin to scientific medical views based upon a Cartesian view of the body. In distinguishing intellectual disability from insanity, I argue that medical practitioners have based their interpretation of
intellectual disability on notions of deficiency and abnormality. Although no longer explicitly connected with sin, these interpretations are thoroughly steeped in moral judgements that connect the continuing presence of "degeneracy" with concepts of heredity. Through an analysis of my siblings' medical records, I show how such notions of deficiency and abnormality become morally and pathologically embodied in contemporary medical interpretations and perceptions of people with intellectual disabilities.

In chapter four, I argue that a pervasive and implicit regime of reason underlies these medical interpretations of intellectual disability. By associating reason with specific intellectual and linguistic skills and capabilities, and assuming that these are necessary attributes for producing meaning and engaging with others socially, intellectually disabled people have been assessed, categorised and interpreted as lacking that which is deemed essential for both normal humanness and human sociality. Through an analysis of the role that intelligence tests have played in the diagnosis and assessment of intellectual disability, I show how such assumptions continue to pervade clinical interpretations of intellectually disabled people. Once again, I draw upon my siblings' records to elucidate the role that such assessments have played in rendering meaningless, bizarre, and irrelevant the practices that intellectually disabled people utilise to express themselves and engage with others socially. By not recognising or engaging with these symbolic practices, I argue that medical and psychological practitioners have consequently ignored or dismissed the capacities for mutuality and intimacy upon which such people's sociality depends.

In chapter five, I turn to the sociocultural literature on intellectual disability and show how it emerged as a direct criticism of the limitations of these medical and psychological interpretations. Through an analysis of the work of Robert Edgerton, Robert Bogdan, Steven Taylor, David Goode and John
Gleason, I separate the sociocultural study of intellectual disability into three distinct, though inter-related, "schools" of thought. Inspired by the seminal work of Robert Edgerton (1967), the majority of early sociocultural studies of intellectual disability tended to focus on the consequences of stigma, labelling and incompetence for intellectually disabled people. They also focused more exclusively on the social experiences and problems of mildly intellectually disabled people, particularly their adjustment to living in the community. More recently, there has been a shift towards analysing the experiences and perceptions of intellectual disability as a social construction (Bogdan & Taylor 1976, 1982; Manion & Bersani 1987). This second "school" extends into post-structural "discursive" analyses that seek to elucidate the connections between discourses of intellectual disability, institutional practices and identity (Branson & Miller 1989; Cocks & Allen 1996; Johnson 1998). Although different in their styles of analysis, the work of Goode (1980a; 1980b; 1990) and Gleason (1989; 1994) represents a third "school" within the sociocultural study of intellectual disability. By emphasising the centrality of relations and intimacy in encounters with severely intellectually disabled people, Goode and Gleason analyse the conditions that are necessary for such people to engage in meaningful interactions with others.

Despite their greater sensitivity to intellectually disabled people as social beings, constructionist accounts do not often allow for an interpretation of these people as more or other than just a product of these constructions. The studies therefore tend to mask the social and symbolic agency of intellectually disabled people and perpetuate the assumption that such people lack the capabilities to be the independent sustainers and authors of mutuality and sociality. Not all meaning is discursive meaning, and social life incorporates generational and transactional processes as much as it involves the reproduction of certain structural elements. While social and cultural factors
have been instrumental in producing an historically informed and socially constructed interpretation of what it means to be intellectually disabled, and while these have subsequently influenced the practices and forms of relating that exist in clinical and institutional encounters with intellectually disabled people, they do not in themselves capture the totality of what it is to be intellectually disabled, nor what is involved in engaging in social relations with such people. While my analysis of intellectual disability in terms of a symbolic scheme of reason and normality is similar to some of the post-structural and constructionist accounts, I have also been inspired by the interactional analyses of Goode and Gleason in my endeavour to analyse how intellectually disabled people actually express themselves and engage with others socially.

In chapter six I return to my fieldwork notes and the records of my siblings in order to examine the processes through which the symbolic scheme of reason and normality becomes instituted into daily practices and relationships in institutional environments. I also analyse this material with reference to contemporary policies towards intellectually disabled people. This includes normalisation and deinstitutionalisation policies, as well as the practices of behavioural management and individual domestic and vocational skills training. These policies and practices have been shaped by social and clinical interpretations of intellectual disability. They are also informed by legal and structural obligations that influence the ways in which staff are able to engage with their 'clients'. While these policies and practices acknowledged that intellectually disabled people are capable of learning, developing and changing, they also continued to render the intellectually disabled in terms of 'deficiencies'. Constructed as lacking or deficient in particular skills and competencies, intellectually disabled people are treated in institutionalised environments as though they need to be managed and trained to become social beings. As a consequence, very little attention is given to their own
modes of sociality and senses of intimacy; to any intimations that they may have of mutual sociality in everyday life.

In my final chapter, I examine the connection between mutuality, sociality and meaning, and the link between these and the different ways in which intellectually disabled people are perceived and related to. In institutional environments, staff relate to intellectually disabled people on the basis of training and management practices. These reflect legal and institutional requirements of maintaining professional levels of distance, separation and disengagement. As a result, the range of symbolic practices and dispositional behaviours that intellectually disabled people utilise to express themselves are not recognised as such, nor are they engaged with. Consequently, as part of their social training, the people with whom I did my fieldwork have been encouraged to develop particular normative communicational skills. This training occurred specifically during the weekly meetings that took place at the activities centre and group homes, although it was also an aspect of the general ethos of training and management that dominated most aspects of both environments. These practices excluded any requirement that intellectually disabled people relate to and engage with the staff.

In order to perceive the intent and meaning of intellectually disabled people's symbolic practices and behaviours, however, I argue that it is necessary to engage with them on the basis of intimacy and mutuality. It is through relations founded on intimate mutuality that differences are able to be symbolically mediated. It is also through such relationships that mutual forms of sociality emerge and upon which intellectually disabled people's existence as social beings depends. To ignore or deny the pre-existing capacities of intellectually disabled people to generate and sustain modes of mutual sociality and symbolic expression is therefore to undermine their existence as social beings. By juxtaposing modes of sociality within a familial and institutional
domain, it is possible to elucidate the consequences of forms of relatedness based on either intimate mutuality or training and management practices. While chapters one, two and seven conceptually frame this thesis and provide a description of familial and institutional modes of sociality and relatedness, chapters three to six provide an analysis of how notions of deficiency founded on a symbolic scheme of reason and normality have become embodied in clinical interpretations and institutional life.