

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

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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.

