Conclusion

A Place for the Intellectually Disabled

... the innate capacities for sociality may be in individuals, but they are completed only between them.

Michael Carrithers

While meaning and sociality is reproduced and recreated as an inherited interpretation of the world, it is also socially produced. It arises out of shared experiences and interactions such that people's actions and behaviours become meaningful and interpretable as an emergent aspect of their shared sociality. The meaning of intellectually disabled people's behaviour is open to negotiation and interpretation once it is accepted that they have such a capacity, and once they are engaged with in this way. When I first spent time with the people at Xanadu I had no understanding of what they were doing. Their behaviour, actions and emotional expressions seemed *ad hoc* and chaotic. I was an outsider, and while they lacked the tools to articulate and express themselves in ways that were socially familiar and acceptable, I lacked the relatedness with them that was necessary to understand who they were and what were their concerns. Over time, and through sharing their environment with them, as they wanted to be, I began to perceive a coherence to their identities and expressions that could operate as potential sources of mutual sociality. This occurred with Sarah and her beads (pp. 249-250), Cressida's narratives of pain (pp. 310-313), Tony and his glass bulbs (pp. 252-254), Joanne and her newspapers (pp. 248-249), Pearl's alternating acts of aggression and affection (pp. 260, 307-308), Jacky's reordering of furniture (p. 254), Polly's

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circular walks (p. 309), Mary's stories (p. 263), Kate's rocking (pp. 250-251, 261), and Martin's drawings (p. 251-252).

These activities and dispositional behaviours reminded me of my siblings and their jigsaw puzzles, bits and pieces, and incantations. Within the domestic environment that we shared, these behaviours and enterprises became the source of our interactions with one another. They became the means through which our relationships were mediated and, although there were limits to the range of these relationships, there was an implicit understanding that these actions constituted fields of mutuality. They created spaces of disclosure through which mutuality could exist. By being perceived and accepted as symbolic practices, the ways or games through which my siblings sought to be and present themselves produced the specific sociality or form of life that I described in chapter one. It was only through our relations and interactions with one another that these were realised.

In order to perceive their actions and behaviours as socially meaningful I had to relate to my siblings, to be in relationship with them, to share a sociality. I had to perceive, interpret and mediate their ways of being in the world as ones which had their own dispositional patterns and integrity. These were specific, contextual and particular modes of expression, and their sociality remained meaningful, negotiable and communicable only through the intimacy of my actual engagements with each sibling. Because of their restricted and highly contextualised natures, the particular language games that became the vehicles for mutuality required a level of commitment and an intensity of engagement that usually only exists in relations of diffuse and enduring solidarity. The patience, empathy and acceptance that is necessary to engage with another who has very idiosyncratic and limited dispositions is one that is difficult to create, particularly in a work environment. Yet this is exactly what is necessary for intellectually disabled people to be recognised as, and to
become, social beings. The development of sustainable forms of sociality for intellectually disabled people therefore requires some very special circumstances, and ones that are not able to be created in the sorts of institutionalised environments that exist at present.

The forms of relatedness that exist in institutional environments preclude the capacity, or indeed necessity, of building relations of mutual sociality. Cultural, structural and legal obligations informed and reinforced these forms of relating. The limited social imagination of institutional environments has made a rational working being the only model of a social human being that it is possible to cultivate. Without mutual sociality, however, humans lose what it is that makes them encultured and social beings. Without this, behaviour also loses its socially meaningful aspect. As Carrithers observes:

The speech we learn only makes sense in respect of the others we learn it from and to whom we direct it. The values in behaviour we acquire are sensible only in the perspective of others, or in our own imagination of others' perspective. Indeed culture, here meaning just largely mental goods, forms of knowledge, and values to live by, which we have learned or created, is intelligible only in its use by people and in respect of other people. Cultures, in other words, presuppose relationships (Carrithers 1992: 30).

Once interdependent relationships with intellectually disabled people are denied, once the necessity of intimate interaction is abandoned, such people's behaviour is perceived as bizarre and abnormal.¹ This is all the more so

¹ There are many ethnographic accounts that illustrate the tendency of social groups to perceive outsiders as strange, inhuman and abnormal (de Castro 1992; Hodgen 1964; Jackson 1998; T. Turner 1995). As Eduardo Viveiros de Castro points out in his study of an Amazonian society, those doing the defining only see themselves as the norm, as real and proper human beings and people (de Castro 1992: 38). The lack of, or distance in, relatedness that

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because intellectually disabled people’s actions and interactions do not generally conform to predetermined cultural patterns and expectations. It is increased in amplitude many times because intellectually disabled people tend to utilise contextualised, restricted, concrete and embodied modes of communication which demand intimate interaction. My experiences at the centre and group homes, introduced in chapter two, made this painfully clear. The consumers were at the activities centre and group homes because their behaviour was perceived and interpreted as asocial and abnormal. Consequently, everything they did and said was treated as such. Therefore there was no development of shared or negotiated vehicles of meaning based on the consumers own creative potential. There was no sense that this was even possible. The activities and practices that were instituted were attempts to inject something socially meaningful into their lives.

The assumption in such practices is that meaning only exists in that which is culturally recognised. As described in chapters three and four, the culturally recognised is defined in terms of a symbolic scheme of reason and normality. However, while humans do things with and to one another in accordance with accepted schemes, there is also an emergent aspect to meaning and sociality that allows for the creation of new patterns of interaction, new relationships, and new meanings. Our capacity to create symbolic systems through which meaning becomes shared, recognised, negotiated and/or mediated is a fundamental component of our humanness. This capacity, the infinite such encounters are based upon tends to preclude the possibility of perceiving these others as like oneself. It is only through contact that these perceptions are challenged, although of course, as postcolonial theorists point out, constructions of others do continue to be based upon initial projections of what is not the self onto the other (Said 1991 [1978]). I would argue however that such post-structural accounts of "self" and "other" simplifies the complexity of relatedness across difference. Like Johnson’s (1998) account of intellectually disabled women, they tend to only emphasis the construction of identity of the "other" as a product of discourse, rather than analysing identity, subjectivity and meaning as an emergent aspect of social practice.
variability and creative potential of patterns that are created by humans, is not limited to "a foreordained dictionary of images to which the world conforms" (Carrithers 1992: 165). Rather, "humans' ability to recognize themes or patterns and variations is . . . infinitely extensible" (Carrithers 1992: 165).

Interpreting meaning as potentially infinite and extendible means that culture and sociality are continually unfolding through processes of interaction and transformation based on social practices and relations (Barth 1966; Carrithers 1992). Rather than meaning inering in an object, or depending solely on rationality, mentalism, and culture as a static entity, meaning becomes a symbolic and emergent aspect of negotiation, use and practice (Bourdieu 1999 [1972]; Saleeby 1994). It arises from relations of power and knowledge as much as it evolves through the intimate interactions of daily life. The institutional and clinical world of intellectual disability is thoroughly entangled in relations of power and knowledge. This is what Johnson's "discourse of intellectual disability" refers to (Johnson 1998: 77; cf. Cocks & Allen 1996: 305-6; Ryan & Thomas 1987: 114). It is what the symbolic scheme of reason and normality produces. The sociocultural critiques discussed in chapter five are a response to the power embodied in such clinical and institutional accounts.

The fact that intellectually disabled people are perceived and treated by clinical professionals and institutional staff in such profoundly disabling ways is an aspect of this power relationship. This is in part a result of the break in relating that takes place when the point of interaction is no longer based on the desire to communicate with, and understand, intellectually disabled people as they are. Rather than seeking the potential and emergent meaning in what intellectually disabled people are doing, clinical specialists seek to understand why and how their actions do not adhere to socially normative behaviours. They apply a meaning to it based on the symbolic scheme of reason and

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normality, assuming in the process that such people are inherently incapable of creating meaning, mutuality and sociality because they lack the supposedly necessary normative social and mental capabilities. Such interpretations rely on associating reason and intelligence with a capacity for sociality. Consequently, what intellectually disabled people do is categorised as abnormal and in need of normalisation. As described in chapter six, a whole apparatus of training and management is introduced in institutional environments in an attempt to foster socially normal expressions and behaviours. These include domestic and vocational skills training. Therefore, relating no longer operates as a bridge of emergent and productive meaning between different people but becomes a one-way process of indoctrination and assimilation.

As described in chapter five, social constructionist and discursive analyses such as those by Bogdan and Taylor (1982; 1989), Goode (1984), Branson and Miller (1989) and Johnson (1998) show how intellectually disabled people are socially perceived and positioned. They show how meaning becomes projected onto "the other" (Johnson 1998: 62-63), and how these ideologies and discourses get incorporated into daily practices by structuring the environments within which intellectually disabled people reside. As Johnson states:

My concern with the subjectivity of the women led inevitably to an exploration of the basis for its constitution by others. Increasingly I became aware that knowledge and the power involved in prescribed associated practices were crucial in determining how the women's subjectivity was 'captured' by others, so the ways in which knowledge, practices and power were exercised in relation to the women became a dominant theme in the study (Johnson 1998: 14).
While I agree with Johnson's arguments about the power of discursive practices to form and inform intellectually disabled people's lives, such post-structural interpretations do not consider the possibility of "knowing" intellectually disabled people outside these formal institutional paradigms. Neither do they interpret intellectually disabled people as more than just "others", the product of projected social meanings. For Johnson (1998: 62-63), even familial relationships are informed by these dominant discourses. Like the social constructionist interpretations of Bogdan and Taylor (1982; 1989), Goode (1984), and Connors and Donnellan (1993), such post-structural accounts do not see meaning and subjectivity as an emergent aspect of social practice and mutuality. Meaning is only socially prescribed meaning. It is how others constitute the intellectually disabled and, although open to diversity and difference due to differences in types of relationships (Goode 1984), meaning is not something which the intellectually disabled are seen to be capable of creating for themselves. It is not something that is seen to be integral to their expressions of self or their mutual encounters with others.

Without denying the importance of these social constructionist and discursive interpretations of intellectual disability I have attempted to move beyond these to show the necessary conditions for creating a meaningful mutual sociality with intellectually disabled people. I have done so by acknowledging that it is through social relations and practices, rather than solely social structures and discourses, that sociality, identity and meaning is produced (Bourdieu 1999 [1972]; 1994). While the symbolic scheme of reason and normality informs institutional and clinical practices, and denies to intellectually disabled people the necessary conditions for mutual sociality, it does not constitute the totality of their social experiences and possibilities.

The people I write about present a challenge to usual concepts of culture. They represent a break with any recognisable re/production of culture. They
do not generate acceptable patterns of behaviour nor do they learn the lessons of culture and reproduce its norms. The gestures of intellectually disabled people are the product of different dispositions, unexpected and unpredictable ones, although once they are engaged with these gestures become meaningful in relation to the person producing them and the context within which they occur. They may not have as their precursor the historical predispositions of a particular culture, but in being made, in being produced, they become a part of that culture. Such gestures do not remain the sole object of that person because in their production these actions and behaviours become part of the wider world, existing beyond the individual person. They are in the world, interacting with it and at the same time producing and shaping it. They exist in relation to others who share this world.

The reorganisation of found objects into the highly treasured and precious collection of bits and pieces that my sister engages in is precisely such an act. The purposeful and patterned encounters with jigsaw puzzles that both she and my brother engaged in also represented such an act. They have both significance for my siblings and reorder the world with which they are interacting. These actions are not performed in a vacuum; they are using the same objects that the rest of us interact with in new and creative ways. They also have an impact on the lives of those who are not intellectually disabled. As kin, we were all involved in their significance and played a role in relation to whatever it was that was signified. The immediacy and intimacy of our relationships with one another were necessary to support them as such. I did not come to perceive the meaning in what my sisters and brother did because of my construction of them as a sister, brother or human being. On the contrary, I came to relate to them as people, as social beings, because we existed within a mutually unfolding social world. I related to them and discovered meaning and purpose in who they were because of our mutual
sociality. This required an intimacy that was founded on our shared encounters with the world, but also on my awareness that what they were doing made sense and had meaning; it resonated with my own attempts to make meaning out of life.

The form of sociality that is therefore required to uphold and develop intellectually disabled people’s sociality depends upon two interrelated factors. It depends upon the acceptance of intellectually disabled people’s actions and expressions as forms of symbolic practice upon which mutuality and sociality can be built. It then depends upon engaging with such people through these very particular symbolic forms, thereby allowing these unconventional behaviours and activities to become the vehicles through which sociality is mediated. While this is more likely to be realised in a familial environment, it is not limited to familial relations. It is almost impossible to achieve in an institutional environment where the practices of training and management founded upon a symbolic scheme of reason and normality are what informs the dominant modes of relatedness. Even in a familial environment, however, it is difficult to sustain sociality over long periods of time. Yet there are aspects of the forms of mutual sociality that evolve out of familial relations which can be built upon in the creation of alternative social environments for intellectually disabled people. The issue becomes one of searching for the means through which a social milieu can be created that recognises, supports and sustains these very particular forms of sociality. The forms of relatedness that are necessary rely upon some sort of vocational aspiration, where the motivation and level of commitment goes beyond an institutionalised service industry founded solely on work as a commodity, and extends to relations built upon mutual and diffuse solidarity. Through such engagements, intellectually disabled people’s specific and restricted symbolic practices and expressions are both recognised and able to be engaged with as such. By denying to intellectually disabled
people the opportunity and capacity to relate to others meaningfully as they are, they lose the very thing which is necessary for them to express themselves as social beings.