Chapter Seven

Relating Across Difference

. . . humans are delicately attuned to one another, and to themselves in relation to others, in a taut web of interaction.

The maintenance or destruction of that web are matters of absorbing interest and overriding importance.

Michael Carrithers

To be human is to be embedded in social relations. Sociality is therefore fundamentally based on interactions between people. Since people with intellectual disabilities are caught up in relations with others—with kin, staff, professionals, and friends—it is on these relationships that an analysis of their identity as social beings must turn. The form that these relationships take, however, varies across different environments, and can be related to differences in the ways that intellectually disabled people are constituted. The different ways in which such people are perceived and constituted both produce and are a product of these relationships. Institutionalised forms of relatedness with intellectually disabled people are based upon and reinforce the symbolic scheme of reason and normality. In such circumstances, intellectually disabled people are perceived as though they are abnormal, deficient and asocial beings. Accordingly, their actions and interactions in the world are perceived as essentially opaque and meaningless. In keeping with the Greek and Latin etymology of the term “idiot”, people with profound intellectual disabilities are perceived as ignorant and private persons. They are seen to lack the rational tools necessary for knowledge and social relatedness.
As a consequence of this perception and interpretation, intellectually disabled people are treated by those in clinical and institutional environments as though they have no capacity for sociality as they are. Through the principles of normalisation and integration, an ethos of management and training is therefore instituted as a means for drawing these people into the social world. The forms of relating that exist in institutional environments build upon these practices and interpretations. In such circumstances, staff are expected to maintain and reinforce a form of relating based on separation and disengagement rather than mutuality and interaction. This lack of mutuality, however, prevents staff from perceiving and engaging with the potential symbolic nature and meaning of intellectually disabled people’s actions and interactions in the world. This subsequently limits intellectually disabled people’s possibilities as social beings.

The consequence of instituting integrationist policies that are themselves based upon the symbolic scheme of reason and normality is that, paradoxically, intellectually disabled people are forced to conform to social norms that they are never expected to be able to uphold. In attempting to normalise that which has been constituted as abnormal, integrate that which has been constituted as radically other, and socialise that which has been constituted as asocial, staff seldom have the opportunity to engage with the intellectually disabled people they work with as anyone other than people to be trained, to be constantly worked on. Relationships that do exist are more akin to assimilationist policies than the true mediation and negotiation of difference that is necessary for the joint constitution of social life.

In this chapter I explore the role that relationships play in the lives of intellectually disabled people. In the first section of this chapter I analyse the weekly meetings that took place at Xanadu and Hervey Street in order to illustrate ways in which institutionalised forms of relatedness come to exist in
practice. These meetings, and the regime of training and management outlined in the previous chapter, serve to heighten, maintain and reproduce differences between the staff and consumers. Relationships between consumers themselves are also considered to be meaningless and socially inadequate. Because their capacity for symbolic representation and meaningful sociality is largely denied, what they do and say is also often ignored. However, my fieldwork experience and my relationships with my siblings have shown me that intellectually disabled people do utilise various symbolic means through which they engage with one another and with the wider world (cf. Gleason 1989). In the second and third sections of this chapter I explore these expressions and relationships and contrast them with the staff's interpretations and perceptions of consumer's purported asociality. The type of complex scenarios that sometimes ensue is illustrated by the narratives of illness and pain that were a regular component of my interactions with many of these intellectually disabled people.

In the concluding section I turn to focus explicitly on issues of sociality and mutuality. The capacity to create symbolic systems and patterns through which meaning is able to be shared, negotiated, mediated and/or recognised, is a fundamental component of humanness and a necessary feature of sociality. It provides the means through which we interact and engage with one another. Profoundly intellectually disabled people are limited in their capacity to create and use symbolic representations. Those that they do utilise tend to be more immediate, concrete, contextual, and embodied. Their capacity for sociality is therefore almost entirely based on the immediacy of engaging with, negotiating and mediating very particular dispositions and symbolic systems. Such negotiation is essential for sustaining and supporting intellectually disabled people's humanness. These ideas return to the starting point for this analysis and thereby act as a summation of the argument.
Managing Meetings

Institutionalised forms of relatedness are generally based on maintaining and enforcing separation and disengagement. These are evident in the formal standards of practice to which staff are expected to adhere. They also exist in the modes of training and management that constitute the daily activities and practices within the activities centre and group homes. During my fieldwork I witnessed the instituting of this form of relating at the weekly meetings that took place at the activities centre and group homes. These meetings were a requirement of the NSW Disability Services Act (1993), according to which all consumers of a service provider are legally required to participate in the decision making and running of services. The staff at Xanadu were particularly frustrated by these requirements. They believed that such policies were impossible to implement, based as they are on an ideology of rights and equality that has little to do with the reality of severely intellectually disabled people’s capabilities. It was not that the consumers were all right as they were. Their differences were still considered abnormal and asocial, and in need of training and management. It was just that including them in decision making processes was seen as a misguided ideal that was impossible to achieve. Yet the area manager who was responsible for disability services in the region had made it clear that these meetings had to take place, that she would be checking the minutes to make sure that they did, and would be using them to “keep in touch with what was going on”.

The coordinator of Xanadu decided that the way to deal with this requirement was to separate the meetings into casual weekly gatherings, where people talked about what they had been doing over the weekend, and to hold the more formal meetings concerning management and decision
making at Xanadu once a month. When the first of these meetings had been held, during a consultancy period with Coopers & Lybrand in mid-1995, the procedure had been to get people to stand when they talked. At the monthly meetings this formality was continued, although there was rarely anything of substance to be discussed, and the consumers rarely had anything significant to contribute, or so the staff believed. Consequently, these meetings usually took the form of a staff member reading through the Standards of Practice outlined in the Act, and asking the consumers questions about these standards.

Apart from recounting these Standards and letting the consumers know what was happening at Xanadu, one of the aims of the monthly meeting was to hear whether anyone had any problems that they wanted to discuss. Mary often spoke at this point and told everybody at the meeting that she was not happy at the centre, that she wanted to leave and spend her days at the group home where she lived instead. She said she was too old to be coming to Xanadu every day and that she did not like it there. Despite the fact that such problems were ostensibly matters to be dealt with, Mary was encouraged by the staff to talk about something positive instead, for example, the things she did like about the centre. This was in accordance with Mary’s behavioural management guidelines. At this point, Mary would retreat into an angry silence, and refuse to participate in the meeting any more. Alternatively, Martin sometimes used these formal meetings to find out about future matters, such as when his parents were to meet with his case manager to discuss Martin’s individual service plan. Martin was told that this was an inappropriate topic for discussion and that he should wait until he returned home to ask about it.

1 Coopers & Lybrand were employed by the NSW Government to oversee the period of transition after the Disability Services Act was passed. It was their job to ascertain whether or not the group homes and activities centres complied with the requirements of the Act, and to outline the necessary steps needed to be taken for them to become fully compliant. An employee of Coopers & Lybrand visited Xanadu over a six week period in 1995, and it was during this period that the first meetings were held that incorporated consumers in the decision making processes at Xanadu.
Having used all his effort to stand, Martin would sink back down into his chair and lapse into silence, along with all the other consumers.

The formalities and agenda of these monthly meetings were dispensed with at the more casual weekly meetings. All the consumers were expected to participate in these weekly meetings, and a regular time was set aside each week for them to occur. They existed as one of the activities that consumers engaged in. The coordinator felt that it was necessary to encourage "more normal interaction between people" and as such he decided that the consumers should sit rather than stand when speaking at the meetings, and discuss things in an informal and relatively casual manner. However, there were still a number of rules that governed the procedure: everyone was to sit in a rough circle waiting for a staff member to begin proceedings; minutes were to be kept as a record of what people had said; only one person was to speak at a time; and the discussion was to remain focused on the topic at hand. Only one or two staff people were usually present at these meetings, the others using this time to catch up on some paper work or sit outside and take a break. A staff member would chair the meeting while I usually took down the minutes. What follows is a description of one of the meetings that took place a few months after I started fieldwork.

It was Monday afternoon and everyone had returned from their morning’s activities to have lunch at the centre. After lunch, once all the lunch boxes had been put away, the tables wiped down, aprons removed, and people toileted, the staff wheeled, encouraged, or guided all the consumers into the television room for the weekly meeting. The minute book was recovered from a filing cabinet in the staff room, and myself and Bill, the staff member who usually chaired the meetings, also took our places at one of the tables in the room. There was no agenda to be followed, so the meeting took the usual form of getting people to say what they had been doing over the weekend. Before Bill
had a chance to formally open the meeting Shauna spoke up. It was her birthday, and she was excited about the party she was having at home after work the next day. Shauna worked shredding paper at Keynton and lived at Hervey Street with four other people, including Mary. Although not a regular occurrence, she had come to Xanadu after work with her co-workers and consequently joined in with the afternoon meeting. Shauna was a bubbly, talkative person and on this particular occasion was addressing herself to Bill. He reminded her, however, that she was to talk to the others present at the meeting, not to him.

After Shauna had redirected her excited monologue to the group of consumers gathered at the meeting Bill asked her to ask somebody else if they would like to tell everyone what they had done over the weekend. Shauna said “Kate”. She did not ask her anything, just said her name. Kate flapped her hands and rocked in her chair, so Bill then asked Kate to ask somebody else to talk and she pointed at me. I told everyone that I had been to Bondi Beach over the weekend and had eaten fish and chips. Martin asked if I had enjoyed myself at Bondi, and then he asked Rachel what she had done over the weekend, but Rachel asked Shauna again. Bill was trying to get Rachel to ask Mary what she had been doing, prompting her by saying, “what do you want to ask Mary?” It wasn’t right to go back to someone who had already spoken. This was against the aim of the meeting where everybody was to have their turn at speaking, at least each of the consumers present.

Without being prompted Mary asked Rebecca to speak, but Rebecca was quite happy sitting back in the lounge cuddled up beside her. Mary then asked Kate, who was still rocking in her chair. At this point Patricia came in to the room and told us that her "friend”—as the person who was paid to take Patricia out shopping or to lunch on a regular basis was officially called—had been to visit over the weekend, and then she wandered back out again. Daniel would
not answer the question when Bill put it to him. He just kept saying "beddies" over and over and flapping his hands. Joanne refused to speak, and Cressida became annoyed about something and did not want to talk either. Nobody said anything much about what they had done over the weekend. Not that this information was unknown. The staff already knew what the consumers had done as it was a regular part of their Monday morning conversations with staff from the houses and the relatives of the consumers. In any case, most of the consumers lived in one or other of these homes and had spent time together over the weekend. However, this was the topic that was instigated by staff to encourage "more normal interaction" between the consumers.

While everyone was sitting around in silence Martin suddenly asked Mandy what she had done over the weekend. Mandy was one of the casual staff members who worked at Xanadu two to three days a week. She had come in from having a smoke outside and was sitting on the bench along the back wall observing the meeting. Mandy seemed embarrassed that she was being asked this question and quickly said that she had been to a friend’s place for lunch before reminding Martin that this meeting was for them, the consumers, and not the staff, and that he should direct his question to one of the others present instead of to a staff member. I had started to write Mandy’s comments in the minute book but she told me not to. She said that staff comments did not form a part of the meeting because the meetings were for the consumers. It was as though the staff were meant to be invisible; that their presence at these meetings were as facilitators, or observers, but not participants. They were there to train, manage and foster interactions between the consumers rather than being potential participants in these interactions.

We sat around for a while after the meeting had ended until one of the other staff members came in to tell us that it was "home time". Everyone was at once animated. Those that could grabbed their bags, headed out to the carpark
and climbed into their respective mini-buses to be driven home. Others were wheeled out. After everybody had gone from the room, Bill turned to me and said: "It's really hard having these meetings because you have to prompt them so much and put words in their mouths, but if you don't do that they'd say nothing. They've got very limited communication, but what else can you do?" Bill had been trying desperately to get the consumers to talk to each other, but conceded in the end that "it was almost impossible!" He thought that it happened occasionally but that it was never really successful.

What surprised me about Bill's comments—especially since he was different to most of the other staff members in that he spent a lot of time with the consumers and genuinely liked them and the work that he did—was that he too was convinced that these intellectually disabled people did not spontaneously talk or interact with one another. While it is true that their ways of engaging with one another were generally idiosyncratic, non-normative and highly particular, the consumers did, however, develop and engage in mutual relations with one another in ways that were meaningful and purposeful to them. Each person had their own specific modes of communication and expression and the consumers engaged with one another through these and through the objects that surrounded them. The shifting allegiances and animosities between the consumers made these relationships highly emotional, changeable, complex and immediate. While it was not always possible to interpret the motivating dynamics of these relationships, they definitely existed, and provided an underlying mood and temperament to every single day. Therefore, rather than attempting to transform the ways that the consumers engaged with others by teaching them socially normative skills and practices that they were not able to adequately sustain, these modes of expression and interaction could have become the grounds from which staff sought to incorporate the consumers into a broader sociality.
However, this was not the accepted or expected role of staff. They were under an obligation to provide the consumers with opportunities to develop their social skills, and learning how to communicate and interact with one another during the weekly meetings was one of these skills. In order to do so required that the consumers learn to absorb a different set of social practices and, just as Cowlishaw observed during her fieldwork with Aboriginal people, "Teaching the discipline and etiquette of meetings and consultation became an end in its own right" (Cowlishaw 1999: 232). This extended into "managing the voice of others", and resulted in a form of "ventriloquism", whereby the participants in the meeting were spoken for and where their own different modes of interacting and participating were rendered irrelevant (Cowlishaw 1999: 234). The weekly meetings at Xanadu had no other purpose than to instruct the consumers in socially normative skills and practices. In this, the meetings became an end in themselves. There was nothing to "meet" about other than to learn how to "meet".

These meetings did not just take place at the activities centre. They were expected to be a regular feature of life in the group homes as well. Although the meetings at Jeffrey Street only lasted a few weeks, those at Hervey Street continued every Tuesday evening for the duration of my fieldwork. During these meetings the house manager, or staff person on duty, would outline the agenda for discussion. This was usually taken from a list that staff had compiled of issues that had come up during the week, although the residents were also expected to contribute to the agenda at the beginning of the meeting. If they forgot to mention something it was left for the following week. The same format that was used at Xanadu was also followed at the house meetings. The meetings were chaired, minutes were taken, and the consumers sat around in a circle and were expected to speak in turn, speak out, and stick to the agenda.
Like the meetings at Xanadu, Mary used these house meetings to raise the problem of her continuing attendance at Xanadu. She also often said that she was unhappy in the house, and that she would prefer to go back to the institution where she once lived. Shauna, who usually had plenty to say, was unusually quiet whenever she was asked if she wanted to say anything at these meetings. Sally usually said "Elvis" or "Rock and Roll" when anything was said to her. Colin rarely said anything, although if a suggestion was made as to where they should go for dinner or what sort of furniture needed to be bought he generally agreed with it. Such household decisions were easily manipulated by the staff, or by the more capable consumers. They only had to ask leading questions or make a suggestion and the other residents would mostly agree. At least publicly. Sometimes the residents complained afterwards but were told that they had to speak up at the meeting if they were unhappy, and that the decision had already been made and agreed to. This happened on one occasion when Jim asked if he could have his girlfriend over for dinner. Colin and the girlfriend do not get on, but rather than opposing the suggestion, Colin agreed to it, only to complain later to the staff person that he did not want this woman coming to the house. She told him that he had to make his point during the meeting, and to the relevant person, rather than complaining to her in private. Despite being good friends, Colin was rather in awe of Jim, and would never have disagreed with him publicly.

There was a lot of discussion at these house meetings about "financial methodology", which was basically a proposal to drastically cut the amount of allocated funding from DOCS in an attempt to deal with a budget deficit. The staff were very distressed about this, especially as it meant that their numbers would be cut and pay conditions altered. The effect on the homes would be that staff would no longer be paid for their night-time shifts, even though they would still be required to stay overnight. The house manager told the residents
that this would mean that they would have to be in bed by 10.30pm. The residents were all rather concerned about this and agreed with the staff that the proposed changes were bad. The staff were quite open about their opposition to these proposals but their comments were "off the record", as were all of the comments they made, and were not included in any minutes. Like the meetings at Xanadu, whatever the staff said was irrelevant as far as these records went. The meetings were solely for the consumers.

While the staff were involved in these meetings as facilitators and minute takers, and even made suggestions at various stages during meetings concerning the running of the household, they were not participants. The residents were therefore regularly reminded that they were to direct their comments to one another rather than to staff. I was also expected to maintain this distance. When in the chair, I had to facilitate the meetings, and direct people to speak, but when Mary said "sorry" to me after a meeting for saying that I could not stay for dinner in response to my having to ask her to stop talking to Shauna, the staff person told her that she did not have to apologise to me but to her fellow residents. Mary then tried to apologise to the staff person but was once again redirected to apologise to the other consumers.

There are two inter-related issues here. One concerns the relationship between staff and consumers; the other is the perception that staff need to facilitate and train the consumers to relate to one another meaningfully. Before analysing the relationships between consumers, I wish to explore more fully the consequences of the institutional forms of relatedness that exist between staff and consumers.

Instituting Relationships based on Disengagement and Separation
Following the weekly meetings at Hervey Street I usually stayed around until after dinner, watching television with the consumers, listening to music, or having cups of tea while sitting outside on the patio. Sometimes I would be shown the latest acquisition, a new table, some clothes or bedding, by one of the consumers. These were more casual moments of the day, and people moved around pursuing their own concerns. Yet there was still an ongoing and pervasive atmosphere of separation and disengagement. The staff did not engage with the consumers as fellow social beings. They were there to manage the house, and spent their time updating records or training consumers to learn domestic living skills. The staff rarely sat down with the consumers and passed the time just having cups of tea together, a smoke, or a casual chat. They rarely engaged with the residents through the residents’ own interests. In fact, the consumers were forbidden to ask personal questions of the staff, and were discouraged from being affectionate and making personal contact. It was all right for the consumers to do this with one another, but not with the staff. Even within the relative intimacy of this home environment, the staff were on duty, and this involved maintaining the relevant and expected training and management procedures. It involved maintaining a form of relatedness based on separation and disengagement.

When I first visited "Keynton”—the paper shredding workshop that operated as part of Xanadu—I met a staff person called Julia who was very passionate about her work. She was disturbed by the departmental policies, the new legislation, and the attitudes of staff, and found herself alienated from her fellow workmates most of the time. Keynton operated out of a large corrugated iron shed situated in a concrete industrial landscape. Despite this, the atmosphere was very relaxed and friendly. The four consumers who worked at Keynton seemed to know the men who worked in the other buildings. They also appeared to enjoy their time with Julia, who sat and
chatted with them, or read and knitted, while they did their shredding. After work, Julia and the consumers would sometimes go for a drive to the local park for a walk, and on one occasion they all went up to the city to visit a woman who used to work with them. While I was sitting in the doorway with Julia, talking and soaking up the afternoon winter's sun, she explained to me that it was illegal for her to touch one of the women in the way that she had just done. Kathy had said that she needed the toilet, and Julia had put her arm around Kathy's shoulder to guide her to the bathroom. In an environment where touch is such an integral component of communication, this legislating against physical interaction only serves to further isolate and separate intellectually disabled people from others in the community. The rule that staff are to refrain from developing personal and emotional relationships with consumers contributes to this atmosphere of separation. Despite these requirements, a small number of staff did become emotionally attached to particular consumers, taking a special interest in their welfare. But the principle creates an environment where this now has to be done surreptitiously.

On one of my first days at Xanadu, while I was helping out at the nursery repotting plants and weeding the garden beds, I was told by two of the staff members not to become too familiar with any of the consumers in case they became attached to me. I was told that their behaviour changes if a staff person whom a consumer has become attached to leaves or is not on duty, and the aim is to maintain consistent behaviour. I was also told not to be affectionate, and that none of the staff were officially allowed to take consumers home with them. Whenever I arrived at the activities centre, group homes, or workshop I invariably felt a pressure to sit and talk with the staff as though I was one of them. While I was not officially a staff person, it was into this role that I was placed. At Xanadu the staff always had their morning tea and lunch in the staff room while the consumers sat in the front room around the tables. Staff would
make sure that those who needed it were medicated and that everyone had their lunches and a drink, but they rarely sat down and ate with the consumers. If ever I did they encouraged me to eat with them instead.

Unlike the majority of staff, I joined in with the activities as though I too were a participant, threading string onto cardboard, playing ten pin bowls, singing karaoke songs, delivering "meals on wheels", or just hanging around watching television, drawing, or having cups of tea. Although I could participate in these various activities I was also expected to lend a hand with their orchestration and assist with toileting and feeding. In this environment there were only two positions that could be occupied; that of staff or consumer. Even the consumers would turn to me at times as though I was one of the staff, asking me if this was "my day on", if they were allowed to have another cup of coffee, or to try and get me to do something for them. So although my status as a volunteer was essentially ambiguous I was constantly drawn into the world of the staff, by their own calling, by the expectations of the consumers, and by the legal requirements governing my actions as a volunteer. It was not possible for me to share the world of these intellectually disabled people, not because of any inherent difference between them and my siblings, but because the structure and expectations of the environment continued to reinforce a division that ultimately separated these people and myself as fundamentally different.

This atmosphere of separation was in accordance with the legal culture of rights and obligations that now exists in these environments (cf. Johnson 1998; McVilly 2000).2 Guidelines for engaging with the consumers were provided by

2 Although this new ideology of rights fundamentally affects the way that staff relate to and treat intellectually disabled people, the problems encountered when relating in ways other than those which have been socially and institutionally sanctioned pre-exists this legislation. Aldo Gennaro—a theatre teacher and performer who was instrumental in the performance of "Madame Butterfly" at the Sydney Opera House in 1979 by a group of intellectually disabled adults from the Lorna Hodgkinson Sunshine Home —was sacked

Chapter Seven: Relating Across Difference
page 301
a combination of the Disability Services Act and its accompanying Standards of Practice, Department of Community Services policies, and individual management plans. The structural and legal constraints of this institutionalised environment perpetuated the interpretation of the intellectually disabled consumers as abnormal and asocial beings in need of training and management. These produced an environment where the forms of relatedness were based on rules of disengagement rather than an ethic of relating per se.

The meetings reflected this relationship of separation and disengagement. So too did the practices of training and management. It was also evident at every moment throughout the day; in the casual encounters between staff and consumers, and the actions and attitudes of staff generally. The wearing of latex gloves by staff whenever they toileted and bathed consumers was one such practice. Despite the rhetoric of hygiene that underlay this practice, there was a definite sense in which staff were keen to avoid all possible physical contact with consumers. They used separate crockery and cutlery, and had their own toilet which was kept locked. On one woman's birthday, the staff at Xanadu covered the chocolate cake with gladwrap so that she could not dribble when she blew out the candles on the cake that they too wanted to eat. Others were said to smell, and the staff argued over whose turn it was to bathe and toilet them. This separation and fear of contagion was deeply etched into staff attitudes and behaviour and reflects the perception that the intellectually

from his position because his way of relating to these intellectually disabled people was deemed inappropriate and unacceptable (Rex Swinton; former Board Member of Sunshine; pers. comm.). The multi-award winning documentary, Stepping Out (dir. Chris Noonan 1980), that was made of this performance and the lead up to it shows Gennaro and the performers relating to one another primarily through touch and physical affection. When interviewed by Caroline Jones on her ABC Radio program "The Search for Meaning", Gennaro cited his own experience of muteness as a child, and his initial inability to communicate when he first went to the USA, as foundations for his particular form of drama teaching. As Gennaro commented, his style of teaching relied on those "little signals" as a type of energy, on creativity and communication through physical and emotional expression, as essential components of the theatrical process (Jones 1995: 113-122).
disabled are somehow inherently diseased, dirty, and potentially contagious. As Mandy said to me one day: "no wonder we get sick working here, getting spat on and pissed on".

This separation was generally combined with an attitude of authority and control, communication taking the form of sarcasm, patronising, hassling and teasing. This was particularly evident at Xanadu, Jeffrey Street, the sheltered workshops and post-school options programme. There were times when I was also drawn into this mode of relating as well, so pervasive and dominating was it. If ever the consumers responded by speaking to the staff in the same way, as Martin had a tendency to do, they were immediately reprimanded. One day, not long after buying a new car, I was discussing with Martin where was the best place to buy a car stereo. I was in the staff room and he had wheeled himself over to the window to talk with me. Two of the other staff asked what we were talking about and when I told them they laughed and said that I could have just made it up as no-one else could understand what Martin was saying. Martin's face and ears were burning and he was visibly upset by their laughter. I felt stranded in the staff room with them, conscious that he was on the other side. One day when I went out with the post-school options group for a picnic I watched as one of the staff members joked around with the young intellectually disabled adults in a rough but friendly sort of way. Every now and then, however, she would look over to me and wink as though the joke was on them and that this was a secret that we shared.

---

3 In her ethnographic account of life in a group home, Mary Howard (1990) also shows that staff interactions with residents were based on authority, control and separation. These were due to the "deficiency view of the resident", Howard argues, and this view was used to legitimise the role of the staff (Howard 1990: 167).

4 Johnson (1998: 4) also talks about this pressure to conform to staff expectations and behaviour, finding that it was almost impossible not to get drawn into the activities of the unit where she did her fieldwork. On one occasion Johnson found herself helping a staff member "manhandle" a woman who was attacking another resident before realising what she was doing. At other times she noticed the amusement or bewilderment of staff at her
Communication amongst the staff was generally about the consumers, not with them, and whenever I came in and said "hello", or made some comment about the day, it was assumed by staff that it was to them that I was talking. When a young woman came to start work at the centre she was introduced to me as another volunteer, and although Mary was standing right beside us both and telling this woman her name, she was ignored. Nor was she introduced. When we went to do ten pin bowling it was only the consumers who took their turn at knocking over the pins. The staff sat back and made sure that everyone had their go, and kept a tally of the score—an aspect of the game that only interested a couple of people—but they did not join in. Delivering "meals on wheels" was a different matter because sometimes a staff person had to accompany the consumer to the door to make sure the duty was performed. Yet even in this activity the staff sustained their separation. They were there to train the consumers to perform this social activity, but were not actual participants in it. On one occasion Mandy complained that she was being "left alone" to do the "meals on wheels" when in fact she was accompanied by six consumers.

These forms of relatedness carried over into the group homes as well. They informed the general practices of staff and were the dominant mode of engagement between staff and consumers. One woman was employed by DOCS to work specifically as a "community integrator" for those living in the group homes. This involved initiating activities such as taking a few of the consumers to the local pub to play pool or the pokies. Sometimes it involved going to a film, out to dinner, or to a fun parlour. The community integrator attempts to engage with the women in ways that were different to the general practices of behaviour management or custodial duty (Johnson 1998: 44). One of the women whom I interviewed—who had worked at Xanadu as the coordinator a number of years prior to my doing fieldwork there—told me that after about four months she began to notice that her own behaviour and attitudes were shifting and becoming like that of other staff members, a process which she found deeply distressing but highly pervasive.
told me that she hated this job; that she found it tedious, embarrassing and frustrating. For her it was not about going out with the consumers but going out to do something for them. It was about providing an environment in which the consumers could be socially integrated with the community. It was about taking them to public places but not about actually fostering integration through staff/consumer relations. The staff saw themselves as the mediators or facilitators of community integration. Despite the obligation on behalf of staff to foster social integration, they did not see themselves as a part of the community to which the intellectually disabled people were supposed to be integrated. Yet true integration requires the fostering of mutual relatedness, and this also has to occur through staff relationships with the consumers.

The expectations and requirements of these institutionalised environments, however, precluded the possibility of developing long term relations of mutual engagement.\(^5\) There was no sense in which true integration, which depends upon the creation of mutual spaces of engagement and joint contributions to the social world, could be produced. Because sociality had been defined in terms of particular and normative dispositional behaviours and competencies, a regime of training and management had been implemented in order to foster the development of this sociality. Yet sociality is fundamentally embedded in social relations. Without relationships born of intimacy, mutuality and solidarity, without the negotiation and mediation of different symbolic systems, it is impossible to produce and sustain a genuinely shared social milieu with intellectually disabled people.

The importance of relationships for social integration and an adequate quality of life has been well documented in some of the recent literature on

\(^5\) Oliver Sacks has stated that in order to perceive the inherently human, intelligent and creative aspect of intellectually disabled people he needed to drop his neurological gaze based on "defectology" and enter into genuine social relationships instead (Sacks 1986: 163-167; cf. Sacks 1995).
intellectual disability (Atkins 1998; Bigby 2000; Fullagar & Hardakar 1993; McVilly 2000; Ralph & Usher 1995; Rapley & Beyer 1996). Keith McVilly (2000: 7) has pointed out some of the "ethical dilemmas" that arise when the professional caring role that staff are employed to perform becomes blurred by a personal relationship. Some of these dilemmas include the potential incompatibility of different expectations associated with these roles, possible power imbalances, and potential conflicts of interest (McVilly 2000: 7). These are very real problems that staff have to contend with, not least because of the overtly legal nature of their responsibilities. These requirements were introduced in part to protect both the consumers and the staff; the consumers from potential abuse by staff and the staff from potential threats of violence from consumers. They were also introduced to protect staff from accusations of abuse. Because of these possible dilemmas, there is a tendency in institutional environments to emphasis the development of social relations of intellectually disabled people with others who are not also staff members.

Both McVilly and Christine Bigby argue that the duty of staff towards people with intellectual disabilities is therefore to increase the number of people with whom consumers have social contact (Bigby 2000: 16-17; McVilly 2000: 17). Bigby specifically stresses the need to enhance "informal support networks" for people with intellectual disabilities arguing that the formal service system cannot "adequately fulfill tasks that require long term commitment, advocacy, or an affective relationship" (Bigby 2000: 17). While these are the sorts of intimate relationships that people usually have with family members and close friends, there is a tendency to criticise the dependency on family members as often the sole social relationship for people...
with intellectual disabilities (McVilly 2000: 6). Rather than rely on family relationships, the aim is to broaden the social network and nurture informal social systems in order to foster friendships, such that the success of community integration is sometimes measured by the number of relationships that intellectually disabled people have with non-staff and non-family members (McVilly 2000: 6). While relationships with people outside the institutionalised environment of the group home or activities centre are important, they are encouraged without adequately addressing both the underlying requirements for mutual sociality and the potential role that staff can play in fostering this. Rather than training intellectually disabled people to conform to normative social standards staff have the capacity to create an environment within which intellectually disabled people are acknowledged as social beings. It is this that can then be extended into the wider community. In order to do this, however, it is necessary that intellectually disabled people be seen as the potential authors and sustainers of mutuality and sociality.

The tragic irony in this situation is that while today the emphasis is on normalisation and integration, those who work most closely with the intellectually disabled are usually the least integrated with them. At the very point where contact takes place between staff and consumer, at this site of potential mutual sociality, the differences and distance between the two groups are highlighted, reinforced and perpetuated. The place where the dissolution of the boundary between intellectually disabled people and others could take place becomes instead the site of its most forceful institution. Bound up in their obligations of a duty of care, and their role in instituting training and management practices, the staff rarely have the opportunity to engage with the intellectually disabled consumers as participants within a shared social environment.
The need to change the dynamics and principles of staff relationships with intellectually disabled people has been addressed by a number of researchers. The emphasis has generally been the need to better encourage integration and normalisation (Brandon 1991: 42-50; Goode 1984: 246; Peters 1980; Ryan & Thomas 1987; Shaddock et al. 1993). As staff members at an organisation for intellectually disabled people, Simone Fullagar and Ken Hardaker argue that relationships need to be based on friendship and mutual respect rather than pedagogic principles. As they write: "We have no choice but to transform the relationship between ourselves as 'service workers' and the people with intellectual disability we support. If we cannot do this, we cannot expect the rest of society to change the way they relate to this group of people" (Fullagar & Hardaker 1993: 43). Despite such criticisms, there has been no attempt on behalf of the formal service system to address these issues. In fact, the implementation of recent policies and practices has made it even more difficult to attain.

About six months after I began my fieldwork I happened to meet Terry, one of the former coordinators of Xanadu. Terry told me that she had eventually left the activities centre because she could not condone the new system that had been implemented while she was away on maternity leave. This was the system of marking off activities and the behaviour of the consumers on a daily basis. As Terry commented, this gave the staff a sense of security at having performed their duties. Training programmes for staff were also introduced at this time, and dealt with behaviour modification techniques, first aid, and issues around sexuality. They were about intervention, training, management and control. Terry stated that never once did she come across material that dealt with issues of communication between staff and consumers. Any communication problems were seen to be between the consumers themselves, as though the relationships between consumers and staff were not
the ones that needed working on. When leaving Xanadu at the end of the year I invited everyone to my place for a BBQ. After endless telephone calls and miscommunication with the coordinator we ended up having to have a picnic in a local park because there were concerns that I would not be legally covered if an accident happened while the consumers were in my house. The consumers were disappointed, as were most of the staff, and it was a sorry end to my year with them as we sat in the patchy shade beneath some scraggy gum trees in a local park with our sandwiches and cordial.
Managing Relations Between Consumers

At Xanadu the staff genuinely believed that the weekly meetings were an attempt to foster "real" and "normal" interactions between consumers. In order to foster such "normal" interactions the staff would try to encourage each person who spoke to ask another person what they had been doing over the weekend. They were encouraged to ask questions, tell narratives about their lives, and be curious about each other. In doing so, the consumers were being directed to express themselves through normative, though highly formalised, modes of communication. This practice of training and instituting normative dispositional communication and behaviour, combined with an interpretation of the consumers as incapable of inherently meaningful symbolic representation and sociality, resulted in the staff being oblivious to, or dismissive of, the often dynamic, complex and socially meaningful interactions of the consumers.

Patricia, more than most of the other consumers at the centre, constantly sought to engage with the staff, often coming into the staff room in order to be with them. She was a small woman, and very strong, and although Patricia did not speak much she was constantly engaging with people through physical contact. Sometimes she would place the top of her head against a staff person's arm, back or chest. She would stand like this for a while, waiting for some response, which usually involved the other person briefly putting their arm around her. At any moment however, Patricia might grab hold of their head and grip it in a neck vice, or hit out at their stomach or arm. Sometimes she would pat them on the head saying "there, there". Patricia would remain like this until asked to leave and replace the rope that was supposed to be kept across the doorway.
This type of interaction did not just take place with the staff. Patricia was a real "mother hen", and was always moving about the room comforting people or assaulting them, one action often following the other in rapid succession. She could give the softest of cuddles to someone who had been crying, or suddenly lash out in anger, swearing and cursing, hitting her head against the table or slamming the cupboard doors. Almost every day the same scenario took place. Polly would be walking around the room in circles, talking incessantly to herself in a high pitched voice. Patricia would get really annoyed with Polly and tell her to "shut up", and then start swearing to herself, hitting the table and her head with her fists, at which point everybody else in the room would get tense and upset. Cressida would visibly retreat into herself, folding her large frame further into the chair as if hoping to disappear from view. Joanne would walk out of the room and sit at the corner table in the television room in order to continue unimpeded in her task of tearing up newspaper. Kate would start rocking even more furiously than usual as though she could drown out the noise and disruption by immersing herself in this rhythmic movement. And Martin would hunch his shoulders up around his ears and tell Patricia to "shut up" and stop upsetting people. At this point Patricia would become even more annoyed and would hit out at people, either verbally or physically, telling them that they were "shits" or "fucks" or hitting them on the back.

It intrigued me when I was told by one of the staff members that Patricia only did this to get attention from the staff. It was hard to convince him that she did it even when they were not present—although, of course, there was always the possibility that she might have been doing it for my benefit. There were many times when the interactions were less violent and unpredictable. One morning when I walked into the local community centre where we had been meeting up once a week I was greeted with sighs of relief from the staff.
as they were short staffed. The two staff members were sitting outside in the sun while most of the consumers were indoors, seated at various tables around the room. They were waiting for their morning's activities to begin, which would entail a visit to the library or the local shops. As I wrote that evening:

They had all had their morning 'cuppa' and were just waiting around. Then Bill came in and gave Martin some crayons to draw with, and it seemed that everyone was to do some craft work if they wanted to. They don't have to do it if they don't want to and most of them usually don't. I sat with Martin and started doing some drawing as well. He was using different colours and doing his usual line drawing. We chatted about my car, and as my partner hadn't fixed up a stereo in it, Martin said he was very lazy and that he'd throw a bucket of cold water over him! While we sat there, Cressida came up and sat behind me and she too started to do a bit of drawing on the edge of the paper. She talked about her new clothes, and her nail polish, and then Kate came and sat with us. Rachel wheeled herself in from outside and we had a full table. Rachel told me she had a new spiral book [for drawing in] and wanted to show it to me but realised she'd left it at home. It was a pleasant morning and I listened and watched as they all talked to one another, touched one another or generally responded to each other's presence. Kate and Cressida were talking quietly about something and seemed to understand each other, but then Cressida turned to me and said that Kate was kicking her. That didn't sound like the Kate that I knew, who was so loving and gentle, but later Rachel told Kate to stop laughing at her. I asked Rachel if she liked Kate and she said emphatically, "no!" I wonder what else goes on between Kate and the others.
This is just one example of the many scenes that I witnessed. There were often shifting allegiances, and strong expressions of friendship or animosity. This was evident in the repetition with which people sat with certain others. It was also evident in the bouts of physical and verbal abuse that a couple of the consumers were wont to display, especially Patricia. Sometimes there were demonstrative displays of affection and pleasure; a big hug, kisses, and holding of hands among friends. Sometimes it just extended to being aware if someone was unwell or in a bad mood. At other times there would be a quiet murmuring, a gentle buzz of acknowledgment and engagement between those present. But more often than not there was just a general sense of being together, of sharing space and time, with a familiarity that dispensed with the necessity of formal interaction. Like Bourdieu’s (1999 [1972]: 78) notion of a “habitus”, there were familiar patterns of dispositions that informed these interactions. This familiarity emerged from their shared environment and was generally based on relating to one another through their bodies, the objects that they shared, and the immediacy of each person’s emotions and actions, rather than the more formal and socially elaborated forms of interaction and self expression encouraged during the meetings. Yet the staff constantly sought to train the consumers to conform to this other, normalised, mode of interaction and expression, and interpreted their actual ways of being and engaging with one another as asocial.
As I pointed out in chapter six, it was expected that the staff be doing things for the consumers, with the aim of providing a socially conforming and normative environment within which they, the consumers, could enter the social world and develop social skills. Accordingly, activities such as cooking, visiting the library, painting, delivering "meals on wheels", going ten pin bowling, shredding paper, tying bits of string to cardboard tags, tracing letters, and gardening were part of the weekly agenda. The meaning and purpose of these activities was assumed to be inherent in the activities themselves. In fact, their very meaning was assumed, and it was this meaning as a socially normative phenomena that was being made available to the consumers. Meaning was thought of as a preexisting social fact rather than a product of interaction and use. It was taken as normative, and these activities therefore conformed to socially accepted modes of engaging with the world. The staff were given the task of introducing these activities as part of an integrationist and normalisation-driven agenda. They set out to train the consumers to conform to these broader social activities. The fact that the consumers did not share these meanings, nor the purpose behind them, was taken as indicative of their asocial and abnormal existence. The accepted belief that they were incapable of creating and utilising potentially meaningful symbolic systems meant that staff did not engage with the consumers on terms set by the consumers themselves.

The consequences of this belief were sometimes complex and often disturbing. In attempts to institute socially normative activities and encourage the development of social skills, the staff often denied or ignored attempts by consumers to communicate to them a sense of self. Even when utilising

---

7 This sense of intellectually disabled people as lacking a coherent and meaningful self is similar to the experiences of those who are physically disabled. Robert Murphy argues in his autobiographical ethnographic account
socially recognisable modes of interaction, such as narratives of self, the consumers were still redirected in their accounts, or else ignored altogether. They were still judged as abnormal and asocial. This was the case with Mary, whose stories about her former life in an institution, the death of her mother and sister when she was young, and her outspoken dislike of the centre and group home where she spent almost all of her time, were taken solely as manifestations of an unstable and psychotic state of mind. They were never encouraged, nor engaged with. It was also the case with Cressida, whose narratives of pain and illness constituted the major form of interaction she initiated with others.

Cressida was in her mid-40s, an Aboriginal woman who lived in Jeffrey Street, the largest of the government funded group homes in the area. Prior to moving into a group home almost ten years ago, Cressida had spent many years living in an institution. I came to know Cressida over the course of my fieldwork, both through the activities centre and from my weekly visits to Jeffrey Street. As we sat there day after day, working at tying pieces of string to bits of cardboard, having cups of tea while waiting for the day’s activities to begin, travelling in the buses, or watching television at her home, I began to notice a pattern in the way she communicated with me. We would be sitting quietly, side by side, the buzz of the local radio station or television filling up the silences. Almost lost in our own reveries I would be drawn back by the plaintive voice of this softly spoken woman telling me that she was ill, that she had a sore, or that her stomach pained her. I noticed that as Cressida said this she would reach out her hand and touch her stomach, which was the part of her body that was generally the cause of this pain. In doing so she would gesture ever so slightly to me, an offering or invitation to touch her also in that place. I would do this, as one does to a person in pain, and Cressida would sit of physical disability, that the social experience of permanent disability is transformed into a state of being a damaged self (Murphy 1990: 85).
back as though enjoying a soothing massage on tired muscles; the relief in her body was palpable. I would ask her if that was better, or if that was the spot which was sore, and she would affirm that it was but would not want me to remove my hand.

This interaction went on for months, and I began to notice that it was not only Cressida who engaged me in conversations over her body, and its pain and illnesses. Others at the activities centre would also come up to me and tell me they were sore or sick. Sometimes, if I was to touch one of them accidentally while helping to take off a jumper or replace a shoe, or just in passing at some stage during the day, they would cry out at me in pain, telling me that it was sore where I had just touched them. Of the twelve who regularly came to the centre, five were frequently evoking pain or illness as part of our interactions. And of another seven people whom I came to know through the group houses, three were often telling me that they were sore, in pain, or unwell.

Very little attention was paid by the staff to any of this behaviour. Like most of the consumers comments and actions, they were seen to be meaningless, purposeless, and irrelevant. They were interpreted as just another manifestation of intellectually disabled people’s abnormal selves. I was told by the staff that Cressida was a hypochondriac, and that the way to respond to her running commentaries on pain, illness and suffering, was to ignore it; to not respond in any way that allowed her to indulge in these "fantasy" illnesses. Cressida would be told to go to the toilet if she complained of having a pain in her gut. That was generally the extent of the staff reaction. There was to be no touching, no caressing, no soothing. There was to be no interaction. There was nothing really wrong with Cressida so there was no real need to respond to her. It was best ignored so as not to be encouraged and condoned. In fact, as a worker, one is seen to have achieved a certain level of professionalism and
control once such behaviour is interpreted as hypochondria. Yet it did not seem to matter how often the staff told people not to make such a fuss out of nothing, they continued to do it. It did not matter how often Cressida was ignored, or told to go to the toilet, she continued to tell me that she was in pain and reach out for me to touch her. One afternoon, when I arrived at the group home where Cressida lived, I discovered that she was in hospital; that she had become increasingly adamant about the pain in her stomach, finally prompting staff to take her to a doctor. It turned out that Cressida had a blocked bowel.

This sequence of events played on my mind for the varying ways in which Cressida and her narratives of pain were being treated. First it was denial; there was nothing really wrong and such behaviour was interpreted as hypochondria. Along with all of Cressida’s behaviour, it was discounted and identified with other disability behaviour. Then came an acceptance that perhaps there actually was something wrong, medically speaking, and the response was to gain confirmation from a practitioner and have the problem dealt with professionally. When Cressida came home from hospital, distressed at having had needles in her buttock and a drip in her arm causing her yet more pain, there was no acknowledgment from staff that she was to be treated with special care or indulged in any way. She was not allowed to play out the role of patient once she had left the hospital. There was never any recognition that it had taken the staff a number of months to respond to Cressida’s signs of distress. In fact it was all forgotten quite quickly. And Cressida’s ongoing narratives of pain and illness continued to be ignored just as they always had been.

Intellectually disabled people often remain voiceless and powerless, without the ability to ascribe to themselves an identity that is not reflective of their social status as abnormal. It is assumed that such people have nothing to say, that they have "no capacity for understanding or conveying their own situation
and experiences" (Atkinson & Walmsley 1999: 209; cf. Bogdan & Taylor 1982; Booth & Booth 1996; Felske 1994). I would contend that the response of the staff to the narratives of pain I witnessed were in part a consequence of such interpretations. They also represent an internalisation of the sick role, as Susan Lea argues (Lea 1988: 66-67). There are so few ways in which intellectually disabled people come to be socially positioned and "known" that they themselves are forced to articulate their experiences and identities within this paradigm. However, rather than interpreting such narratives as negative consequences of labelling, as Lea (1988: 66-67) does, I would argue that intellectually disabled people use these narratives of pain and illness to try to insert themselves into the social milieu. They do so through attempting to create a "shared space of disclosure" (C. Taylor 1985).

Charles Taylor uses this term to describe the space within which the self is constituted, arguing that a shared space of disclosure is based on the various communicational and symbolic means through which people come to be subjects both for themselves and for others (C. Taylor 1985: 271-273). As with most theories of culture and language, Taylor's operates at two, albeit inter-related, levels. There is the constitutive and productive nature of language and culture that can be said to operate at the meta level, at the institutional or pedagogic level, informing and forming persons as particular types of persons according to a normative notion of what constitutes personhood. There is also the "interactional" aspect of language and culture that operates to create shared spaces within which people engage with one another. The former is the level at which the symbolic scheme of reason and normality operates, and within which practices of training and management are instituted. It produces a formal, formalised, and public sense of personhood according to an inherited, institutionalised and socially prescribed interpretation of meaning and identity.

8 I am indebted to Diane Austin-Broos for drawing my attention to Taylor's work.
Taylor argues that within "modern society and culture" people are expected to project and express themselves in an abstract and self-reflective manner, using the rational tools of language to articulate their experiences in a readily acceptable and socially recognised form (C. Taylor 1985: 280). This contemporary form of a space of disclosure evolved out of a Western preoccupation with the role of reason and contemplation in the expression, and indeed experiences, of the self and personhood (C. Taylor 1985: 280). However, as Taylor argues, this preoccupation "utterly banishes earlier views of specialised spaces of disclosure, so that they even cease to be fully comprehensible" (C. Taylor 1985: 280). While true of other cultures and historical periods, this is also true of the contemporary institutional encounter with intellectually disabled people.

Not only are the ways that intellectually disabled people disclose a sense of themselves rendered incomprehensible, but staff are also expected to teach these people to learn how to conform to normative modes of self-representation and expression based on the central roles of reason, self-reflexivity, and language. Reason and intelligence have been associated with the capacity for sociality and, in order to become social beings, intellectually disabled people need to be trained to develop the necessary spaces of disclosure through which they can present themselves to others as social persons. The staff are under an obligation to encourage this as part of the expectations of community integration and normalisation. They have a sense of what such a space of disclosure entailed, based on historical and cultural perceptions of selfhood, and sought to train the development of these normative interactions and communications during the meetings. The intellectually disabled consumers were being asked to constitute themselves in terms of a particular space of disclosure, a narrativized space based upon
impersonal accounts of their lives rather than on an embodied and immediate response to others.

However, there is also another level at which language operates, and it is through the combination of both that the narratives of pain I was witnessing can be understood. Language, according to Taylor, is also used as the vehicle through which people are brought together. Language in this sense does not just apply to spoken narratives. It refers to all symbolic activity or "forms" (C. Taylor 1985: 272-272). It can therefore include the symbolic practices of intellectually disabled people, including gestures, bodily contact, the utilisation of objects, and behavioural dispositions. While restricted in their applicability and range of expression, such symbolic practices do have the capacity to generate forms of sociality. Through interacting with others on the basis of these symbolic practices and disclosures it is possible to create a "rapport between us . . . what one might call a public space, or a common vantage point from which to survey the world together" (C. Taylor 1985: 273). This then becomes a way of domesticating a space, of transforming it and making it livable. My sister's bits and pieces constitute such an activity, as did my brother's use of jigsaw puzzles. These actions were ways of making things happen in the world, of transforming the world. They became the vehicles through which meanings could be mediated and sociality shared. They created a "public space" through which we could interact with one another.

The narratives of pain I witnessed during my fieldwork were an attempt on behalf of intellectually disabled people to create a rapport, a common vantage point or "shared idiom" (Herzfeld 1997: 3), through which to view the world. Through Cressida's actions and narratives of pain I was drawn into a common space, a space of pain and illness that I was both familiar with and with which I could empathise. Her narratives became one of the means through which we related to one another, and in this sense created a level of intimacy and

Chapter Seven: Relating Across Difference
page 320
understanding that made our shared world meaningful and social. Like Geertz's (1993a [1973]) notion of culture as a system of shared symbols, these narratives of pain were generated by a shared symbolic system. They also generated this symbolic system in the process of being articulated. It was, in Wittgensteinian terms, a language game that worked—or that should have worked—and the creation of this space of disclosure gave Cressida the possibility of presenting herself as a public self, a social being, a person who existed within a meaningful and socially shared world.

The added complexity to this situation, however, is that in attempting to constitute a shared space of disclosure through the sick role and narratives of pain and illness, intellectually disabled people like Cressida are not engaged with because what they do and say is not taken as potentially meaningful. Unlike the sick, who can get better, these people are perceived as permanently "unwell". Like the sick, they must work towards their own rehabilitation but can never actually attain it because they are always and already constituted as outside the social. In the process, their narratives and expressions of self are disregarded. They cannot have anything meaningful to say, therefore, the staff do not engage with them as such. Even when expressing herself according to the normative standards of pain and medical illness, and even when utilising recognisable narratives of self, Cressida’s attempts at communication were put under suspicion. The act misfired because there was no faith in the possibility of mutuality. Cressida was denied the valid and authoritative status as a person capable of representing herself to others. Her attempts to enter into the social milieu through her body and narratives of pain and illness were invalidated and her status as a person both participating in and creating a shared social

world were consequently denied. Interestingly, my siblings never used such narratives of pain and illness at home, perhaps because there were other means through which they and their actions were socially legitimised.

By denying and ignoring these narratives of pain, illness and selfhood, staff undermine one of the means for mutual interaction that intellectually disabled people's sociality and identity depend upon. While the intellectually disabled people at Xanadu and the group homes were continually engaging with one another, the lack of opportunity to develop shared spaces of disclosure with non-intellectually disabled people limited the consumers' possibilities for exploring a broader, socially inclusive sociality and self-identity. When extended to all their forms of symbolic practice, this loss of interaction and mutual relatedness with non-intellectually disabled people prevents the development of shared or negotiated symbolic systems or language games based on who intellectually disabled people actually are. By denying intellectually disabled people valid and potentially shared spaces of disclosure within which they are able to express themselves as social beings, the constitution of sociality as a joint and mutual endeavour is consequently undermined. The opportunity to sustain a mutuality with non-intellectually disabled others contributes to intellectually disabled people's humanness, and their capacity to exist in the world as social beings. To prevent this is to lock intellectually disabled people into a world where their symbolic, communicative and social capacities are limited to interactions with their fellow intellectually disabled consumers. It also results in practices of training and management that are utilised as the means for drawing these people into the social milieu.

The people with whom I worked, and my brother and sister, all expressed themselves in an immediate, embodied, concrete and highly contextual manner. This was as much an attribute of the narratives of pain that Cressida
utilised, and the incantations and running commentaries that my sister engaged in, as it was an aspect of other ways of acting in the world. These expressions occurred through the objects that surrounded them, such as the jigsaw puzzles and books and bits and pieces of my siblings, or the beads, drawings and glass bulbs that people were using at the centre. Sometimes these expressions of self occurred through their bodies, their emotions and the gestures that they made towards one another. Robert Desjarlais comments that such forms of expression and engagement represent an "acutely tactile engagement with the world", arguing that they involve a "poetics of exchange, confrontation, finite acts, and momentary occupations" that are fundamentally different to socially conventional narrative forms of expression (Desjarlais 1996: 86-7). Due to the loss of spatial, political and economic grounds upon which people are usually able to assert themselves, Desjarlais argues that mentally ill and homeless people are often forced to rely on their bodies as the primary means for expressing themselves and articulating their experiences. As Desjarlais puts it: "With the loss of many possessions, and the public slant to physical movements and functions, the body becomes, at times, the most prominent instrument of engagement, awareness and retrospection" (Desjarlais 1996: 78). The narratives of illness and pain I witnessed during my fieldwork represent such tactile modes of engagement, as did the acts of friendship, frustration or animosity that were expressed through physical encounters. These involved such things as holding hands, sitting side by side on the couch touching one another, or patting someone gently on the head, as much as it involved pinching, hitting and scratching another person. Such

10 The possibility that experience is an historically and culturally constituted phenomenon rather than an "existential given" is one that Desjarlais also examines in his ethnographic encounters with homeless and mentally ill people (Desjarlais 1996: 72). Desjarlais claims that Western notions of "experience" are predicated on notions and forms of reflexive interiority, a narrative flow, hermeneutic depth, individual agency and transcendence. All of these aspects and expressions are thought to reflect and inform the true self (Desjarlais 1996: 73). Desjarlais argues, however, that experience and selfhood are instead the products of social, political, cultural and environmental factors.
modes of engagement were constantly utilised by the consumers in their relations with one another, but they were also enacted by the consumers in their encounters with staff. Patricia did so when she came into the staff room and grabbed hold of a staff member. David did so when he came up to a staff person wanting them to scratch his head. Cressida did so when reaching out to staff to touch her in the place that was sore. For others with whom I worked these expressions of self involved patterns of dispositional behaviour, such as walking in circles, rearranging the furniture or rocking in a chair. These were the dispositions and patterns through which they expressed themselves, and through which meaning could potentially be negotiated and mediated. These were the actions through which mutuality and sociality could be developed and sustained.

Yet the potential for mutual sociality with intellectually disabled people based upon such symbolic practices is not recognised or aspired to in institutional environments. The ethos is entirely one of training and management; of conformity and assimilation to normative standards. In this situation, whatever intellectually disabled people do and say is interpreted as abnormal and meaningless. Maryla's collection of bits and pieces is labelled obsessive compulsive; Cressida's daily accounts of her bodily aches and pains are dismissed as hypochondria; Mary's stories about her mother and sister's deaths, and accounts of her experiences at various institutions, become indicative of an oncoming psychotic episode; Kate's rocking and singing are thought to be obsessive and disruptive; Joanne's silence and separation from others while tearing up newspaper an aspect of her autism; Patricia's alternating aggression and affection an expression of her intellectual disability combined with an abusive past. By interpreting these dispositional acts as solely pathological and abnormal, and ignoring attempts on behalf of the consumers to use these as the basis for their encounters with others, the
opportunity to produce a genuinely shared and interdependent mutual sociality with non-intellectually disabled people is lost.

Through instituting practices of reason and normality staff encourage the development of decontextualised skills and behaviours. These are based upon a particular concept of what it means to be human, of what it means to be a person. In our society, the attributes and practices that are most highly valued are those of rational, conceptual, abstract thought, and of productive and economically viable work. Intellectually disabled people do not fulfil these expectations, and their expressions of self and encounters with others often remain localised, contextual and immediate rather than abstract and decontextualised. Relationships are usually with those in one's immediate environment, with those with whom one comes into direct contact. These include other intellectually disabled people and staff, as well as family members and family friends. Intellectually disabled people's concerns are often immediate, emotional and bodily. While the possibilities for their sociality and mutuality are limited by these restrictions, it is possible to engage with intellectually disabled people and develop socially meaningful relationships through these actions in an inclusive rather than exclusive way. This requires accepting their ways of being as legitimate and their expressions of self as potentially meaningful. It requires engaging with them through intersubjective, mutually inclusive relationships.