

First published in *Social Science & Medicine*, volume 53, issue 9 (2001).

Published by Elsevier

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Social Science & Medicine online at:

http://www.elsevier.com/wps/find/journaldescription.cws_home/315/description

**Accommodation, Resistance and Transcendence:
Three Narratives of Autism**

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Acknowledgments

The author would like to thank the Apex Trust of Autism and the University of New England for their support in funding this research. Thanks are also due to the Autism Association of Queensland and its staff for their cooperation. A special thanks is extended to the parents of children with autism who participated in this study. The author would also like to thank Virginia Gray, Pat Jobes and Eric Livingston for their comments on earlier drafts of the manuscript.

Abstract

This paper presents a narrative analysis of autism. It follows much of the literature on illness and narrative by emphasising the moral quality of illness narratives and the role it plays in creating coherence out of the disordering effects of autism on family life. In particular, the significance of narratives as “moralizing antidotes” to the experience of marginality and their linkages to the cultural “master narratives” of science, politics and faith are stressed. The three narratives presented display both conformity and non-conformity with the official narrative of autism offered by the autistic treatment centre where the research was based. Accordingly, they are described as narratives of accommodation, resistance and transcendence.

Introduction

The last decade has witnessed the growing popularity of narrative analysis in sociological studies of illness. This is especially the case in research on chronic illness, where it has been applied to a variety of diverse conditions including AIDS (Marshall and O'Keefe 1995), bowel disease (Kelly and Dickenson 1997), cancer (Bell 1999, Del Vecchio Good et al. 1994, Frank 1995, Mathews et al. 1994), physical disability (Borkan et al. 1991, Mattingly 1998, Phillips 1990), infertility (Becker 1997, Riessman 2000), epilepsy (Good and Del Vecchio Good 1994) mental illness (Capps and Ochs 1995, Hyden 1995, Saris 1995), multiple sclerosis (Robinson 1990), musculo-skeletal disorders (Garro 1994) and rheumatoid arthritis (Bury 1982, Williams 1984).

This article presents a narrative analysis of autism, a disability that has not previously been examined from this perspective. As such, it seeks to contribute to the growing literature on chronic illness and narrative analysis. However, it also has a second purpose. Unlike most studies using narrative analysis, it attempts to extend the method to the study of families of individuals with a disability. This is especially appropriate in the case of autism, which presents severe problems to families as they attempt to carry out daily life. In particular, this article examines how parents of autistic children attempt to construct coherence out of the disorder their child's disability brings to their families and their own identities as parents. It especially focuses on the moral aspects of narrative reconstruction and presents three case histories as examples of narrative analyses of autism.

Review of the Literature

Recent research on illness narratives has emphasised the moral qualities of the experience of illness and disability (Becker 1997, Frank 1995, Hyden 1995, Williams 1993). In particular, illness and disability are viewed as representing a threat to the afflicted person's moral status for a number of reasons. First, there is the lingering belief derived from the Puritan tradition that views illness as an indication of sinfulness (Williams 1993). Second, Western culture strongly values self control and illness threatens the ability of individuals to maintain their competence in dealing with the routine tasks of their daily lives (Becker 1997, Williams 1993). Finally, normalising ideologies are strongly embedded in Western culture and illness represents the failure to live up to the "normal" standards of health, and, therefore, places the individual in a morally problematic position (Becker 1997, Hyden 1995).

As a consequence, the narrative reconstruction that follows the onset of illness or disability has a strongly moral quality. To begin with, the experience of illness is one that typically causes the individual to examine their life in terms of their fundamental moral values (Hyden 1995). The loss of taken for granted assumptions about good health, and the inability to continue with normal activities, requires the individual to reflect upon the things he or she values in life and to assess their responsibility for the illness and the meaning it will have for their future. Narrative reconstruction also provides a "moralizing antidote" to the experience of abnormality that illness produces (Becker 1997). The experience of being different is often severely disturbing to ill individuals and their narratives usually involve accounts of their efforts to live as normally as possible under the circumstances of their illness (Becker 1997). In constructing these narratives, individuals may draw upon cultural categories such as family or personhood that have a strongly moral quality (Becker 1997) and link these to "master narratives" such as science or faith that

justify their attempts to deal with their illness (Mishler 1995). Furthermore, because these narratives are shared with others, they create a community that witnesses the sick person's attempt to live successfully with their illness (Frank 1995). In short, narrative reconstruction involves an attempt by the individual to make sense of his or her experience of illness and demonstrate that he or she is a morally adequate person who attempts to lead a normal life under difficult circumstances.

Despite the emphasis on normality and morality that is commonly found in narrative reconstruction, the outcome of this process does not necessarily endorse the status quo. Instead, narrative reconstruction may also involve resistance to normalising ideologies (Becker 1997, Bell 1999). One reason for this is that medicine is often ineffective in treating many forms of chronic illness, a fact that may undermine biomedical authority. This, coupled with recent ideological shifts toward individual sovereignty and citizenship, may support ideas of resistance to medical personnel (Williams 1993). Furthermore, the experience of marginality involved in illness may provide individuals with their first opportunity to examine previously taken for granted assumptions about the nature of normality. This problematising of normality may encourage openness to new definitions of normality that may be at odds with those accepted by medical practitioners or wider society (Becker 1997). Finally, many individuals will cope with their illness with the help of various support groups who may resist standard normalising ideologies. These groups may help the individual to validate alternative definitions of normality that are oppositional in nature (Becker 1997, Bell 1999). In short, although the experience of illness necessarily requires the individual to confront their loss of normality and morally come to terms with that fact, the narrative reconstruction of their experience does not necessarily mean that they will accept mainstream

definitions of normality. Rather, narrative reconstruction may produce resistance as well as conformity.

As previously noted, illness narratives have a strong moral component that is the result of individuals' attempts to reconcile the distress caused by their sense of difference due to their illness and their desire for normality. Autism presents especially formidable challenges to families because its symptoms are disruptive of the most basic of aspects of daily family life. Accordingly, many parents of autistic children view their families to be abnormal and experience severe distress as they struggle to reconcile their experience with autism with their desire to have a normal family (Gray 1997). Although the concept of the "normal family" is inherently problematic, it nonetheless represents an important working concept for the parents of autistic children and is shared by many treatment providers (Gray 1997). Such providers - in this case an autistic treatment centre - have concepts of family normality that provide the basis for a co-authored narrative of normal family life. Such a narrative provides the basis for a moral resolution of the parents' experience of having an autistic child. Not everyone, however, may share the same narrative. The experience of autism must be placed in the context of each parent's life and reconciled to his or her central values (Hyden 1995). In some cases, this can be accomplished in the context of narratives co-authored with treatment providers that reflect professional ideas of normality. As previously noted, however, illness narratives also contain aspects of resistance to normalising ideologies. This paper discusses three narratives of autism, all of which reflect a strongly moral focus, but differ in the ways that they accomplish a narrative reconstruction of the experience of autism.

Methodology

The results reported here were taken from an ongoing study of the social experiences of families with autistic children living in the Brisbane metropolitan region of Australia. The sample for this study consists of thirty-two parents of autistic children (twenty-three mothers and nine fathers), representing twenty-three families. The number of children with autism in this sample was twenty-four and comprised of sixteen males and eight females. Their median age was eight and their degree of impairment ranged from moderate to severe. Most had experienced the onset of symptoms before the age of two and were diagnosed by four. The socio-demographic characteristics of the participating parents were generally representative of the Australian population and are presented in Appendix 1.

Depending on their preferences, participants were interviewed either at an autistic treatment center or in their homes. Interviews varied from one hour to over four and a half-hours in length. Most participants were interviewed individually, although in a few cases participants preferred to have their partners present. The decision to interview the parents separately was based on several considerations. First, the interview included questions about spousal relations and the presence of the parent's partner was assumed to be inhibiting. Second, as other researchers have noted, women and men often have very different perceptions of their family's experience with illness (Greil 1991). Because one of the aims of the study was to examine possible effects of gender in parenting a child with autism, it was necessary to elicit parents' individual narratives in separate interviews rather than to interview them as couples for their jointly constructed family narratives.

The data were gathered in semi-structured interviews designed to elicit the parents' personal accounts of raising a child with autism. The order of the questions was based on an implicit sequence of biographical experience that started with the family's early experience with autism, addressed their present situation and then asked them to project their situation into the future. This sequence of questions dealing with past, present and future is a widely accepted narrative form in Western culture and is commonly applied in narrative analyses of illness (Becker 1997, Garro 1994, Hyden 1997). This emphasis on temporality also distinguishes narrative analysis from related qualitative methods such as ethnography and grounded theory.

Although narrative analysis has become a popular approach to studying the experience of illness, there is only a limited consensus about the nature of the method (Bell 1999, Hyden 1997, Mishler 1995, Riessman 1993). Several authors have attempted a typology of illness narratives that have considered such factors as grammatical structure (Mishler 1995) and thematic content (Hyden 1997). The type of narrative analysis used in this study is of a thematic nature and corresponds to what has been termed "illness as narrative" (Hyden 1997). As such, it attempts to convey the personal experience of illness through the thematic analysis of the participants' stories of illness.

The present paper presents a narrative analysis of three case histories. As Bell (1999) has argued, narratives are not constructed by isolated individuals. Rather they are jointly constructed by social actors and institutions, in this case an autistic treatment centre. The first case history is described as a narrative of "accommodation" because it conforms to the normalising ideology based on biomedicine offered by the autistic centre where this research was conducted. A large majority of the cases in this study would conform to this description.

Narratives, however, also incorporate the "changing terrains of resistance and power" in the situations where they are created (Bell 1999). Accordingly, the remaining two case histories are respectively described as narratives of "resistance" and "transcendence" because they offer alternative narratives based on politics and religion. Although they were found among only a minority of the case histories, they represent the most common alternatives to the narrative of accommodation. The three cases histories presented here were selected not only because they represent the most common categories of narrative accommodation and its alternatives, but also because they provide particularly articulate and thematically coherent examples of illness narratives.

Finally, several members of the staff at the autistic treatment centre, including two senior administrators and two social workers were selected to be interviewed. They typically were involved with the evaluation and diagnosis of the children at the treatment centre, and, especially in the case of the social workers, had ongoing access to the parents through casework sessions. The interviews with the treatment centre staff sought to ascertain the staff's perspective on the families' biographical experiences and place them in a specific organisational context.

Themes from the Data

The Role of the Autistic Centre and the Narrative of Normality

The setting for this research was a state autistic centre that specialised in behaviour modification for the treatment of children with autism. Through its social workers, the centre also provided counselling services for parents designed to help them cope with their child's disability. Although the activities of the centre have changed in recent years, at the start of this research clients usually maintained a lengthy relationship with the autistic centre, often for a decade or more. As a consequence, the autistic centre usually played an important role in the treatment of the children's autism and the parents' adjustment to it.

Research on human service agencies has reported that the staff of such agencies usually possess an illness ideology relevant to the disorder they treat (Davis 1982, Gray 1993, Scott 1962). These typically include beliefs about the etiology and prognosis of the disorder, the nature of their clients and their means of adaptation to the illness. The autistic centre in this research was no exception to this tendency. The centre staff generally accepted a biomedical model of autism that assumes it to have a biological, probably genetic etiology, and a poor prognosis. The staff also followed a grief model of adaptation for the parents that assumed that the onset of autism in a child to be a loss comparable to a death, and that parents would typically follow an emotional pattern of "peaks and troughs" as they gradually came to terms with their loss. The staff also believed that although the symptoms of autism could be lessened through behavioural modification, they could not be completely eradicated. Therefore, almost all autistic children would require permanent supervision and many would eventually be institutionalised.

From this perspective, the role of the staff was to help parents accept the disability of their child while helping them come to terms with their guilt and grief. The autistic centre offered parents a narrative of autism that absolved the parents of moral responsibility for their child's autism in the following ways. First, they emphasised the biological basis for autism and assured the parents that their child's disability had nothing to do with their child raising abilities. As one staff member said:

We would say to them that first it is important for you to understand that nothing you have done has caused your child to be autistic, and, in fact, from what we can see you handle this child, this very difficult little kid, extremely well. You've done all the right things for a child with no handicaps, but your child, we think your child is autistic.

This type of statement was particularly useful to parents because of the past popularity of psychodynamic explanations for autism that attributed its etiology to parent/child interaction during infancy. Although such explanations are totally discredited today, they occasionally re-emerge in the popular and professional literature on autism, and present an additional burden to parents who are already stressed in coping with feelings of guilt for their child's disability.

Second, the staff of the centre discouraged parents from being excessively concerned with the cause of their child's autism. The staff believed that although the parents' interest in the cause of their child's autism was inevitable and natural, it was not beneficial for them to be obsessed with it. Though willing to discuss the issue with parents, they preferred to de-emphasised the significance of etiology. As one staff member said:

I try and present it fairly simply... At assessment stage I really try and avoid the 'x' chromosomes and all the rest of it. I say that there is a lot of research going on in the area at the moment. We still don't really know the cause of autism but what we do know is that it is an organic condition. The

organ that is affected is the brain. It is not caused by what you've done to the child or the emotional environment of the home or anything like that. At the assessment stage I think that is about enough.

Instead, the staff prefer to shift the discussion away from etiology toward the practical problems of treating the disorder. Although this often raised the difficult issue of prognosis, the staff attempted to emphasise the unpredictable nature of the child's future and to couple it with the need for parental support and involvement. The previous staff member described what she would say to parents in the following way:

I don't know what your child is going to be like when he grows up I cannot predict that. I can tell you that autism is a serious handicap and it's going to affect him all his life. It means he is going to need special support and assistance as he develops. But where he develops to depends on a whole lot of things including his general intellectual ability, and the sort of programming he gets along the way.

In this way, the staff believed that the parents' energies could be put to the more constructive use of treating their child's symptoms rather than obsessing with the reasons for its cause.

Finally, the staff social workers tried to convince parents that despite their child's autism, they were still a normal family. The position that the staff tried to convey to the parents was that they were a normal family to which something abnormal - the birth of an autistic child - had happened. This position was supported by discussing the issue during casework sessions with the staff social workers, by the gradual improvement of the child's symptoms during treatment, and by encouraging the family to try to live as normal a family life as possible within the limits imposed by the presence of an autistic child. The latter meant encouraging families to engage in typical social activities, to give their other children the attention they need and to have other children if their autistic child was their only child. One of the staff's senior administrators described a normal life for a family with an autistic child in the following way:

The parents have a reasonably workable marriage and have a commitment to it. Parents are mutually supportive and not kind of using the disruption in the family just as more fuel for an unhappy relationship. And they have a relatively normal family life, you know, all those negotiated routines work for pretty well everybody and they're not constantly disrupted. There is more than one child in the family so there are some non-autistic children in the family, and those other children feel that they get a fair share of time as well, and are reasonably satisfied, and the family goes out and does things. The family reaches out, there are friends and relatives so they're not isolated.

In conclusion, the autistic centre offered a narrative of autism that minimised the parents' blame for their child's disorder, enlisted them in its treatment and tried to convince them of their family's normality. Generally, the staff were successful in their efforts and most parents eventually accommodated a version of the staff's position in their own narrative reconstruction of the experience of raising an autistic child. There were, however, two problems with this narrative account from the parents' perspective. First, like all biomedical explanations for illness, an etiological account of autism that stressed its nature as a biological accident did not provide an overarching moral explanation for their suffering. Second, although parents were involved in the treatment of their child through behaviour modification, their role was somewhat dependent and passive in that they were still heavily reliant on the autistic centre for information and treatment. This, coupled with cultural values emphasising parental activism in raising children and the limited success of the staff in treating autism, meant that the narrative of autism presented by the autistic treatment centre was one that was open to contestation by parents.

The next section of this paper will present three parental narratives of autism. The first is one where the parent accepts the narrative of autism offered by the autistic treatment centre and the next two are ones that dispute it. Accordingly, they are described as narratives of accommodation, resistance and transcendence.

Accommodation: The Case of Mr. McKinley

Joseph McKinley was the father of three children, the oldest of whom had autism. Mr. McKinley had a middle ranking administrative position with a local company and his wife's work was centred on home duties and childraising. They lived in a middle class suburb near their elderly parents and maintained a close relationship with them. They were deeply committed to their immediate and extended families and much of their time was taken up in family activities, an involvement that was seriously complicated by their daughter's autism.

Although most children with autism begin to display symptoms after their first birthday, Mr. McKinley's daughter, Jane, displayed severe symptoms from early infancy. In particular, her behaviour was characterised by excessive crying and screaming, rigid body posture and difficulty in feeding. As in many cases of early onset autism, a diagnosis was not quickly forthcoming. The McKinley's original general practitioner denied that there was a disability, dismissed the problem as part of the typical difficulties that first time parents experience, and assured the McKinleys that Jane would soon grow out of her problems. When the situation did not improve the McKinleys obtained a referral to a medical specialist and began the long process that would eventually lead them to the autistic centre and a diagnosis of autism. At the time of the initial interview with Mr. McKinley, Jane was eight years old and had a full time placement at the autistic centre. Her symptoms had significantly improved with treatment, but her behaviour was still very difficult and she frequently had problems with eating and toileting. She was also destructive of property and would sometimes engage in public tantrums. Her parents were grateful for the progress she had made up to that point, but felt that their control over Jane was precarious at best.

The McKinley's family situation was difficult but stable. Jane's symptoms were disruptive of domestic routines, affected her mother's health and caused problems for her father's career. Nevertheless, the McKinleys were emotionally supportive of each other and took solace in the presence of their two younger children and the family activities they could manage, given the restrictions presented by their daughter's autism. In short, the McKinley's were experiencing a difficult situation, but coping with it reasonably well. They were also a family who approximated the autistic centre's idea of a typical family's experience with autism.

To begin with, Mr. McKinley's account of his family's experience was compatible with the autistic centre's position that the etiology of autism is biological. In particular, he attributed his daughter's disability to birth trauma. When asked about the cause of the disorder, he replied:

[A] biochemical imbalance of the brain, or a lack of vital oxygen just before birth. I was at the birth, it was a bit slow. There's got to be some[thing] like this.

Like many other parents, the etiology of his daughter's autism had been a source of considerable concern to Mr. McKinley. However, by the time of the interview, he had largely abandoned the hope of ever finding the reason for his daughter's autism and tried to accept the situation as a much as possible.

Now I just accept the thing, well, "Mine was the lucky number. It had to happen to someone and we've been given the challenge and that's it"... It happens that the statistics show [it occurs to] one in a thousand girls, I think. That's it... my number came up.

Instead of being concerned about the cause of his daughter's autism, Mr. McKinley had turned his attention to coping with the problem and aiding in his daughter's treatment as much as possible. He

was especially supportive of the centre and donated considerable amounts of his time to various centre projects. He also worked hard to maintain a normal family life, although he acknowledged the difficulty of attaining this ideal.

You don't have a normal family life. Our whole family has to cater for Jane's needs. You can't go out very often as a family. You've got to watch [her] a lot more closely, a lot more closely than normal for [someone] her age. I think the whole family has more or less had to shoulder the burden and that includes [my sons].

Nevertheless, the McKinleys tried to maintain as many family activities as possible. For example, they took take Jane to church on a regular basis and shopping when necessary. However, their family activities were mostly restricted to situations where they could limit the effects of their daughter's misbehaviour. This usually meant doing things around the house or taking outings in familiar places.

What we like to do is we try to have a totally relaxed weekend... I like gardening and spending time in the backyard and the boys like [to do] it with me. They're out in the back there and we're just normally relaxed and have, you know, a picnic out in the backyard sometimes, and then they love it. The kids really love it. We often go down [to a local park] and, you know, it's only a couple of minutes drive, and we sit down there and like to have a picnic, or I'll buy them an ice block or something like that, and that's the only way on holiday time... because there's no point in going anywhere [with Jane].

The two preceding comments illustrate Mr. McKinley's assumptions about what constitutes a "normal family life", the ways in which his family fails to live up to that standard and the strategies they use to approximate it. Such accounts are not simply descriptions of divergence from normality. Rather they constitute moral claims by individuals that demonstrate their efforts to live up to society's expectations despite the difficulties inherent in doing so (Becker 1997). In this particular case, Mr. McKinley's assumptions about normal family life are consistent with the autistic centre's description of the normal family. They also describe the McKinleys' attempts to

contain their daughter's problems while pursuing typical family activities, and, thereby, demonstrate that they accommodate the autistic centre's view that they are a normal family to which something abnormal has happened.

Finally, there is also considerable similarity between Mr. McKinley and the autistic centre's negative outlook regarding prognosis. On the one hand, Mr. McKinley noted his daughter's young age, the progress that she had made thus far and his reluctance to rule out the possibility of further improvement. On the other hand, he was well acquainted with the medical literature, aware of the severity of his daughter's symptoms and fearful of the problems they would face when she reached adulthood. As he said:

I don't know what the future holds. I, like I say, I'm always hoping that she will come out of it. And while she's not going to be brilliant [I hope] she'll be able to go down the road and do her shopping, cook for herself, and, you know, dress herself and bath herself. But I know, deep down, that's being fairly ambitious... Maybe she's going to be forced into a home, but I, you know, I don't like the home that I've seen. I don't know. If I... were a millionaire, I suppose I would be able to pay for someone to look after her full time, but I... can't do that either.

Mr. McKinley's description of his daughter's future is necessarily inconclusive. In fact, illness narratives are often incomplete because the individual's situation has not been resolved. Instead, descriptions of the future often involve a "subjunctivizing" element in which various outcomes are presented as possible future resolutions for their illness (Becker 1997). In Mr. McKinley's case, he describes one optimistic outcome where his daughter attains the sort of living skills that will allow her a modest degree of independence. However, he also notes the possibility that such hopes are unrealistic and attempts to distance himself from an answer by noting the difficulty her youth presents for accurately predicting her future. The position of hoping for the best, but preparing for

the worst, was a common orientation to the future among the parents of the autistic children in this study and one that was regarded as realistic by the autistic centre staff.

In conclusion, Mr. McKinley's narrative of his daughter's autism is largely compatible with that of the autistic centre. It includes a belief in the biological etiology of autism, the attempt of his family to live a "normal family life" and the acceptance of a poor prognosis for his daughter once she has reached adulthood. Mr. McKinley's narrative reconstruction of his daughter's autism is one that is successful at dealing with many of the stresses his family encounters and at obtaining services to deal with his daughter's problems.

There are, however, two problems with this account. As previously noted, accepting the autistic centre's position requires a degree of passivity on the part of the parents and it does not provide a moral explanation for their child's suffering. Although, these problems are usually overcome through casework with the staff social workers, successful resolutions of these problems are not always possible. In such cases, parents may develop their own narratives of autism that do not accommodate that of the autistic centre.

Resistance: The Case of Mrs. Dawson

Beth Dawson and her husband Richard were a professional couple in their mid thirties. They had three sons, the oldest of which, Robert, was severely autistic. Robert was nine years old at the time of the research and had been a client at the autistic centre for nearly six years. Although he had made some progress and become more orderly in his habits, he had virtually no language, was sometimes aggressive and had significant problems with toileting, eating and a variety of other

behaviours. At the time of their initial interview, the Dawsons were in a situation that was stable, but highly stressful, as Robert's behaviours were extremely challenging and his care dominated much of their family life.

Unlike most parents of autistic children, who are usually the first to suspect a problem with their child's development, the Dawsons were initially reluctant to believe that their son might be disabled. In their case, the child's grandparents and nanny first detected the problem. As Mrs.

Dawson said:

We actually thought he was quite bright because he used to do really odd things like sit in his cot and play with a toy for half an hour, [sitting] still, you know. He'd look as if he was reading a book when he was really tiny, a year old. [He] used to do odd things... My parents were the ones, and the lady who looked after him, they were the ones that put the pressure on us about something being wrong.

Despite the expressed concerns of her parents and nanny, Mrs. Dawson was reluctant to believe that there was a problem. She rejected her parents' worries and dismissed the nanny rather than accept the possibility of a developmental disability in her son. However, these efforts at denial were futile, as Mrs. Dawson could not avoid an increasing awareness of her son's problems. His failure to attain normal developmental milestones, her general practitioner's comments and her own knowledge of childhood development, led her to suspect that something was seriously wrong. Nevertheless, she was reluctant to seek an assessment and suffered considerable stress due to her ambivalent feelings. Despite being an intelligent and normally capable individual, Mrs. Dawson found herself increasingly unable to cope with the situation. She described her state at that point:

I was totally hysterical. I was absolutely out of my tree. I wouldn't go to the shops. [My husband] used to go shopping. I went back to work when Robert was one, which says something because I

didn't get any sleep. See, he didn't sleep until he was about seven or eight, and the only time I ever felt really sane was when I was at work, 'cause I could forget about it. I could switch off.

As her son's symptoms intensified, Mrs. Dawson denial became increasingly untenable. Finally, when he was about three and a half, the Dawsons had Robert assessed at the autistic centre where he was diagnosed as autistic and admitted into the treatment program.

For many parents in this study, their child's diagnosis of autism was received with some degree of relief because their child's problems had finally been understood and some form of therapy made available. However, Mrs. Dawson was emotionally devastated by her son's diagnosis. Her self esteem, which had been strained by her son's problems, was now further damaged by the confirmation of his disability. In particular, her experience with the diagnostic process was emotionally traumatic for her. As she commented:

I had to go in front of this panel of people and they asked me what was going [on]. So I went through the hoops and it was really awful...I remember being fairly intimidated. I remember that I threw up all the way home after the advisory [panel]... It was fairly heavy going.

In addition to the trauma of the diagnosis, Mrs. Dawson disagreed with the autistic centre's analysis of her son's prognosis. She felt that the staff were not perceiving Robert's abilities and were excessively negative about his prospects for improvement. She was also uncomfortable with the autistic centre's grief model of parental adaptation. Although she agreed that having an autistic child was, "like you've suffered a death" in the family, she found the centre's illness ideology to be overly transparent and rigid while providing little practical help. As she said:

They always wanted to fix me up for my grief, you know, look after my grief... I got people saying, "Oh well", you know, "you're in stage three now" or something like that... I mean, I'd never say that to anybody in a fit. And, you know, "You will pass through this", and that sort of thing. And I'm

thinking, "Well, damn, I might stay angry for ten years if I want to"... People were that way, patronising rather than practical... If they had said, "Look, I'll come and do your dishes for you, that'll help your grief", I would have said, "Sure, that would help my grief an awful lot".

As previously noted, a potential problem for some parents is that accepting the autistic centre's position involves a degree of passivity that threatens the cultural values of parental activism and responsibility. Although most parents come to terms with this problem, not all do, and Mrs. Dawson was one who could not accept the role she believed the autistic centre offered her. She described that period after her son's diagnosis as being her "lowest point" and she believed that the autistic centre saw her as being as troubled as her child. Rather than accommodating what she perceived as the autistic centre's expectations for her, she chose a path of resistance.

In particular, she began to educate herself about autism and disability services. She also began to seek out other parents of disabled children who were dissatisfied with available services. In this way, she began to empower herself and engage her problems as an activist. As she commented about her experience at the autistic centre:

I came away from there determined that I was never going to be put in that situation again. I was never going to be put in the situation where a doctor could... just sort of breeze in and take control and say, "You will do this, this and this". So I started to look for a group that would give me advocacy skills...

She succeeded, both in finding an advocacy group and in influencing public policy towards disabled children. As she said:

I've changed legislation. It was really amazing... I'm really proud of it... The organisation I joined, we wrote a Special Needs Policy, which used a consultative approach. We involved service providers from all over the place so that... parents could begin to take control. Three of us worked on that. We got Commonwealth funding for a project officer and... we set about doing it and we did it. Oh yes, the legislation's changed... We achieved what we wanted to achieve.

This success not only changed the provision of services for the disabled, but Mrs. Dawson's view of her own abilities as well. As she commented:

I just, I sort of got my self-confidence back. That I wasn't an idiot. I wasn't an "autistic mother", which is what they tended to want to call you, because you feel you're at your lowest point. And, I mean, you think service providers think you're... as big a problem as your child.

For Mrs. Dawson resistance provided an antidote to the role of an "autistic mother" that she found repugnant. She rejected the passivity she perceived in such a role and asserted herself through political action. As a political activist, she reconfigured her own narrative of reconstruction in a way that empowered her and offered her resistance to the power of a particular normalising ideology. Her son was still severely autistic and her life was very stressful. However, she felt that she was once again in control of her life and that she possessed a sense of direction.

Transcendence: The Case of Mrs. Collins

Jane Collins was a formerly married woman in her forties with three children. She was unemployed and lived with her children in a modest house in a new subdivision. Her youngest daughter, Susan, was severely affected by autism, the symptoms of which had been apparent early in her infancy. At the time of this research, Susan was eight years old and had been under treatment for her autism for nearly five years.

Despite the efforts of Mrs. Collins and various therapists, Susan had made only limited progress with her autism. Her symptoms included poor language abilities, severely destructive behaviour towards property, aggressiveness and marked social withdrawal. In fact, she was one of the most severely affected children in this study. The severity of Susan's problems was reflected in the precautions her mother had to take with their house to prevent her from damaging the house and its furnishings.

This house isn't really a normal house because it's been specially built... I've had those windows [fixed so] she can't climb out... The handle on the [kitchen] door is high on purpose to keep her out if we have to. I've got special locks on the kitchen cupboards. I've got an extra door put into the laundry [room] if I have to lock the laundry up. I've got an extra door into the kitchen so that I can shut the kitchen off completely. I've got all the handles up really high and I've got the same sort of window in her bedroom as what I have in the [living room]... I had [the yard] fenced. I wasn't moving in until those priorities were achieved.

The effects of Susan's autism on her family, however, went beyond the damage she caused to their home. Her problems also prevented Mrs. Collins from obtaining employment outside her home, and, consequently, the family was forced to live modestly on a government pension. Being out of the paid workforce also meant that Mrs. Collins was isolated at home and found it difficult to

establish a social life beyond her family, a problem that was exacerbated by being a single parent.

In fact, her only regular social engagement was a church that she and her children attended.

In several aspects, Mrs. Collins' perspective on her daughter's autism conformed to that of the autistic centre. While, she agreed that Susan's autism had a biological basis, her case was somewhat unusual because medical tests had revealed a genetic abnormality. Despite the fact that this particular abnormality was not conclusively linked to autism, Mrs. Collins believed that it contributed to her daughter's autism. As she said:

I'll tend to go along, I think, with what the experts say. [However] there is a strange thing with Susan... because she's got a chromosome abnormality.. each cell has got an extra bit. [Her neurologist] in Brisbane tends to think that Susan's chromosome abnormality on its own is enough to make her different... I don't know.

Mrs. Collins' expectations for Susan's future were also similar to the autistic centre's general prognosis for autistic children, as she had few expectations for her daughter's complete recovery and expected her to end up in some sort of institutional care. Although Mrs. Collins had experienced some success in working with Susan using the behavioural management techniques advocated by the autistic centre, she was well aware of the severity of her problems and pessimistic that they could ever be completely overcome. She would continue to try, but her expectations for future success were guarded. As she said:

I'm the sort of person who probably would never give in. I'll get tired and I'll get down and I'll get jack of it, but I don't think I'd ever give up... [but] you know she'll never be normal. You know you can't have that, but you'll keep on trying because she's learning. If she wasn't learning, I don't think I could.

Although reluctant to think about Susan's future situation, she hoped for an eventual residential placement that would be well suited for her daughter's needs.

The autistic [centre] has opened up an adults' place now. Maybe that'll be hopefully something for the future. That sort of environment... because I would hate to put her into [institutional] care. I'd hate the thoughts of when that day would ever come, because she blossoms in a family life... She thrives on normality and... I'd love her to get more normal situations, but people don't want it.

Although Mrs. Collins agreed with the autistic centre's perspective on the causation and prognosis of autism, she had difficulty in accepting their view of family normality. Rather than seeing her family as a normal family to which something abnormal had happened, she perceived her family life as extremely abnormal. Her judgement was based on the severity of Susan's symptoms that isolated her family from others. As she said:

[We] don't have a family life. Not a normal family life. You can't really ask people over because it doesn't always work. They either don't like little kids or they've got little kids of their own and Susan will probably hurt them... By the same respect, you cannot go to someone else's house unless you know [them] really well or unless they've got a yard [where] she can't pull all the plants out of or something. And you couldn't go for very long [and]... you can't get baby sitters.

Other factors also contributed to Mrs. Collins' isolation. As previously noted, she was divorced and unable to work. She was also more isolated than many other parents with autistic children were because she no longer had regular contact with the autistic centre. She lived outside the area serviced by the centre, and, consequently, her daughter was enrolled at a local special school for the disabled. Because this school enrolled children with other disabilities, Mrs. Collins believed that she had little in common with the other mothers at the school. As she said:

I just wish we had an autistic school or something up here. Just because I find that [I'm] not even accepted by the mothers of [other] handicapped children. They can't understand autism... and therefore you can't even share your innermost thoughts... because they do not understand... You're

barred from normal life and you're also barred from [the] handicapped because they're not the same. You don't fit into either.

Mrs. Collins, however, had one social outlet, the church that she and her children attended. She described herself as a "born again" Christian and viewed her faith as being one of the main reasons that she could continue to cope with her daughter's autism. The church was one of the few places where she could take her daughter and have her treated with tolerance. The church also provided her with a broader understanding of her daughter's autism.

As previously noted, one of the problems with the biomedical explanation of autism favoured by the autistic centre is that it lacks an overarching moral explanation for autism. Although the staff at the autistic centre work hard to relieve the guilt of the parents by focusing on their lack of culpability and by redirecting their moral concerns toward cooperating with their child's therapy and living a normal family life, they still lack a theodicy of suffering that could derive meaning from a parent's experience of having an autistic child. Mrs. Collins found this meaning through her faith. Rather than accepting autism as a biological accident without moral purpose, she found a transcendent meaning in her daughter's disability. As she said:

When you're feeling negative you'll say, "Why do you [do] anything?". But I'll say, "No, it's not why me?". I'll say, "She's special, she's a special person. I'm her mother. She's my child. She's here for a reason." Susan, once you've seen her, you're never the same again. You might either love [her] or you hate [her], but you will never be the same person ever again. Susan is her own witness to the world. She is herself for all her faults like we all are, but she teaches so many lessons... I just say, "Yes God, that's your will, that's your reason, that's your purpose. It blesses so many people. It makes people think. People are never the same again". And once you've met an autistic child, I'll guarantee you'll never, ever, be the same again.

In this way, her daughter's autism has been invested with a strong moral dimension and Mrs. Collins' narrative reconstruction of her experience has been given a greater meaning than that

offered by the biomedical explanation for autism. This is a narrative of suffering that transcends the paradigm of abnormality and adaptation to seek a higher purpose. For Mrs. Collins it validated her struggles with Susan's autism and gave her a reason to continue with her efforts.

Conclusion

This paper presents three narratives of autism. The first, a narrative of accommodation, conforms to the version offered by the autistic centre where this research was conducted. It is a narrative that approximates the biomedical account of autism and endorses professionally based ideologies of adjustment and adaptation. The other two narratives reject accommodation in favour of alternative versions of the experience of parenting an autistic child. One is a narrative of resistance where the parent redefines herself in terms of political activism and personal assertiveness. The other is a narrative of transcendence where the parent draws on her religious faith as a way to make sense out of her daughter's suffering.

These narratives have been presented as attempts to grapple with the moral dimension of the illness experience. This emphasis on morality has been based on several assumptions. First, it is assumed that the experience of illness is one that runs counter to deeply embedded cultural values of normality. In other words, being ill or disabled - or in this case, parenting a disabled child - makes an individual different from others and causes him or her significant emotional distress as they experience the role of the "other" (Becker 1997). Second, it is also assumed that narratives of reconstruction are more than ethically neutral descriptions of dealing with the practical problems brought about by illness. Instead, narratives are moral accounts of how people try to live normal lives despite the difficulty of their circumstances (Becker 1997). They invoke a "moral frame" that

gives their daily activities an ethical dimension that goes beyond a merely technical account of adaptation (Williams 1993). Furthermore, such a moral frame is not an isolated individual production, as the individual's culture presents him or her with a series of more or less viable accounts that link them to a "master narrative" and a wider community of individuals who share that narrative (Hyden 1995, Williams 1993).

In this paper, the parents have presented three narratives of autism, each of which draws upon culturally sanctioned master narratives such as science, politics and faith. These narratives of accommodation, resistance and transcendence have also led to their authors to alignments with different communities. In the first case, the parent has become actively involved with the autistic centre. In the other two cases, a group of political activists and a church have served as alternative communities of support. In this way, and using these resources, the parents have narratively reconstructed their experience of parenting an autistic child.

These findings are significant for two reasons. First, they apply narrative analysis to a disability – autism – that has not been previously approached from this perspective. Second, they present narratives of family members of disabled, in this case, the parents of children with autism. As parents, they are especially affected by their child's disability and its threat to culturally sanctioned ideas about family normality and their role as caregivers for their children. For these reasons, the parents' narratives of autism offer valuable insights into the nature of narrative reconstruction in the case of a severe disability and the role of family members in the experience of illness.

References

Becker, G., 1997. *Disrupted Lives*. University of California Press, Berkeley.

Bell, S.E., 1999. Narrative and lives: Women's health politics and the diagnosis of cancer for DES daughters. *Narrative Inquiry* 9, 347-389.

Borkan, J.M., Quirk, M., Sullivan, M., 1991. Finding meaning after the fall: Injury narratives from elderly hip fracture patients. *Social Science & Medicine* 33, 947-957.

Bury, M., 1982. Illness as biographical disruption. *Sociology of Health & Illness* 4, 167-182.

Capps, L., Ochs, E., 1995. *Constructing Panic: The Discourse of Agoraphobia*. Harvard University Press, Cambridge Massachusetts and London.

Davis, A., 1982. *Children in Clinics*. Tavistock Publications, London and New York.

Del Vecchio Good, M-J., Munakata, T., Kobayashi, Y., Mattingly, C., Good, B.J., 1994. Oncology and narrative time. *Social Science & Medicine* 38, 855-862.

Frank, A.W., 1995. *The Wounded Storyteller*. University of Chicago Press, Chicago and London.

Garro , L.C., 1994. Narrative representations of chronic illness experience: Cultural models of illness, mind, and body in stories concerning the temporomandibular joint (TMJ). *Social Science & Medicine* 38, 775-788.

Gray, D.E., 1993. Negotiating autism: Relations between parents and treatment staff. *Social Science & Medicine* 36, 1037-1046.

Gray, D.E., 1997. High functioning autism and the construction of normal family life. *Social Science & Medicine* 44, 1097-1106.

Greil, A.L., 1991. *Not Yet Pregnant: Infertile Couples in Contemporary America*. Rutgers University Press, New Brunswick and London.

Hyden, L-C., 1995. In search of an ending: Narrative reconstruction as a moral quest. *Journal of Narrative and Life History* 5, 67-84.

Hyden, L-C., 1997. Illness and narrative. *Sociology of Health & Illness* 19, 48-69.

Kelly, M.P., Dickenson, H., 1997. The narrative self in autobiographical accounts of illness. *Sociological Review* 45, 254-278.

Marshall, P.A., O'Keefe, P., 1995. Medical students' first person narratives of a patient's story of aids. *Social Science & Medicine* 40, 67-76.

Mathews, H.F., Lannin, D.R., Mitchell, J.P., 1994. Coming to terms with advanced breast cancer: Black women's narratives from eastern North Carolina. *Social Science & Medicine* 38, 789-800.

Mattingly, C., 1998. *Healing Dramas and Clinical Plots: The Narrative Structure of Experience*. Cambridge University Press, Cambridge.

Mishler, E., 1995. Models of narrative analysis: A typology. *Journal of Narrative and Life History* 5, 87-123.

Phillips, M.J., 1990. Damaged goods: Narratives of the experience of disability in American culture. *Social Science & Medicine* 30, 849-857.

Riessman, C.K., 2000. "Even if we don't have children [we] can live". Stigma and infertility in south India. In: Mattingly, C. and Garro, L., (Eds.). *Narrative and the Cultural Construction of Illness and Healing*. University of California Press: Berkeley.

Riessman, C.K., 1993. *Narrative Analysis*. Sage Publications, Newbury Park, California.

Robinson, I., 1990. Personal narratives, social careers and medical courses: Analysing life trajectories in autobiographies of people with multiple sclerosis. *Social Science & Medicine* 30, 1173-1186.

Saris, A.J., 1995. Telling stories: Life histories, illness narratives, and institutional landscapes. *Culture, Medicine and Psychiatry* 19, 39-72.

Scott, R.A., 1962. *The Making of Blind Men*. Russell Sage Foundation, New York.

Williams, G., 1984. The genesis of chronic illness: Narrative reconstruction. *Sociology of Health & Illness* 6, 175-200.

Williams, G., 1993. Chronic illness and the pursuit of virtue in everyday life. In: Radley, A., (Ed.). *Worlds of Illness: Biographical and Cultural Perspectives on Health and Disease*. Routledge, London.

Appendix 1. Selected Socio-demographic Characteristics of Parents

Sex	Female	72%
	Male	28%
Education	Tertiary	33%
	Graduated High School	41%
	Attended High School	21%
	Less High School	4.2%
Occupation	Housewife	50%
	Professional, Managerial and Technical	26.6%
	Clerical and other Administrative	10%
	Tradespersons	6.7%
Family Income	Over \$60,000	5%
	\$40,000 to \$49,000	15%
	\$30,000 to \$39,000	5%
	\$20,000 to \$29,000	40%
	\$10,000 to \$19,000	20%
	Less \$10,000	10%