

***At risk of homelessness: disabling discourse and practices with families of disabled children***

**DISABILITY STUDIES: THEORY, POLICY AND PRACTICE**

**THE INAUGURAL CONFERENCE OF THE DISABILITY STUDIES ASSOCIATION**

**4<sup>TH</sup> September – 6<sup>th</sup> September 2003  
Lancaster University  
Lancaster**

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The motivation for this presentation comes from an experience earlier this year. This experience forced me to reflect on the discourse around families when they are no longer able to care for their disabled child at home. I am conscious here that whatever words I use – for example, care for their children at home, or no longer able to look after their child at home, disabled children or children with disabilities – represents a particular perspective, a particular world-view of expectations of families, of parents, of parenting, and of disabled children.

The experience was this. I was asked, on behalf of two government departments in NSW, a state of around 6 million people, to facilitate a four hour meeting with selected senior policy personnel and senior regional staff.

One department is the Department of Community Services, which bears the legislative responsibility for the safety, health and wellbeing of children and young people and has the statutory responsibility to intervene if a child is at risk of, or is being maltreated. This department is still known to families and others as ‘the welfare’.

The other department is the Department of Ageing, Disability and Home Care. This department has recently also become a service provider, providing state financed services to people with a disability. Previously there was a funder-provider split with this department only being responsible for policy development and service funding not delivery.

These two departments have been involved in a long drawn out attempt to develop a joint protocol to cover disabled children when they can no longer live with their families. At a stalemate, with neither Director-General prepared to sign off on suggested protocols, a facilitator

was called for in an attempt to break through the impasse. I was that facilitator.

Participants coming to the meeting were asked to submit prior to the day at least one case study that represented involvement by both departments. Choice of problematic or successfully resolved cases was left up to the participants. My choice of words here comes from the series of emails that flowed from the organiser of the day. In the event, eight case studies arrived by email to all participants at around 5pm the day before the morning meeting. Two of these in fact involved the same young person, however with quite different accounts provided by representatives of the two departments – it took me several readings of both to see that this was the same young person.

Come now to the morning of the meeting. Given a difficult topic – and several years of attempting to get resolution – participants came with surprising good will and a willingness to move forward. Working in pairs – one from each department, each pair focused on one case study to answer the following questions:

1. What drivers determined intervention? From both care and protection and disability services.
2. What assumptions underpinned this intervention? From both care and protection and disability services.
3. What challenges existed to intervention? From both care and protection and disability services.
4. What possible solutions could have been framed? From the perspective of both care and protection and disability services.

The desired objective of the meeting from both departments' perspective was to come up with a draft protocol – despite my hesitation that such an outcome was

possible. I thought if we could get as far as identifying assumptions underpinning how the cases had been managed, then, at a later stage, the joint departmental working party could continue its business and articulate jointly agreed principles to underpin future practice.

What the meeting achieved is for others to judge. The issue it raised which requires much closer examination and which is the focus of this presentation is this:

**What is the status of a disabled child or young person whose family is no longer able to care for them in the family home?**

**And what discourses surround determination of status?**

I use the word status advisedly – this was and still appears to be the sticking point in attempting to reach a resolution, which would offer safety, health and wellbeing to these children, and dare I say, a degree of comfort to their families.

Why is the child or young person's status so central? Departmental discourse is framed in the first instance around legislative responsibilities. For the Department of Community Services their statutory responsibility is to protect children and young people. For the Department of Ageing, Disability and Home Care their legislative responsibility is to provide and/or secure services for families with children and young people with a disability, which meet the requirements of the NSW Disability Services Act.

So the status of the child or young person becomes central to departmental thinking about which department

holds responsibility for the particular child or young person.

The status of the child or young person appeared to be thought of in several and often contradictory ways:

1. They are experiencing harm or at risk of harm so need to be removed from a neglectful or abusive situation.
2. Their parents are exhausted, or in crisis, or no longer able to 'cope' so an alternative care arrangement is required to 'relieve' the parents.
3. They are at risk of homelessness – the parents are saying they can no longer care for their child – or they have been 'encouraged' to say this (and more of this later).
4. They are seen as victims of a system – where their parents have not had adequate supports and now have no choice but to relinquish (another problematic term) their child to the care (so-called) of the state.
5. They are indeed already homeless as parents are no longer prepared or able to provide a home – the child may have been 'left' in respite care.

Chillingly, without exception each case evoked a response from participants that the family and child or young person were victims of 'the system'. In other words, participants unanimously agreed that with better supports, better collaboration and cooperation between departments, the situations presented would not have occurred. In their words, these children and young people would not now need out-of-home placement.

So what discourses prevailed and what influence do these discourses have on the lives of families and their disabled children? I plan to cover three, which I see as critical to the ongoing process of further disabling disabled children and their families.

1. Belief that family care is the desired and achievable alternative for every disabled child – family and community care discourse
2. Belief that parents no longer able to care for their disabled child are ‘guilty’ of not being able to meet their child’s needs – neglectful/ abusive parent discourse
3. Belief that systemic responses will provide a safer and more secure future for a disabled child or young person – systemic superiority.

***Family and community care discourse***

**Belief that family care is the desired and achievable alternative for every disabled child – family and community care discourse**

Over the past two decades the state has become increasingly co-involved with families in providing for family members with a disability. There is a heavy policy emphasis on supporting families to care for their children at home. This is not surprising as it is generally thought to be a cheaper way to care for those who would otherwise require expensive residential services. It is probably fair to say that the current ideological position is that children with disabilities should be cared for in the family home.

The argument for the right to a family environment for children with disabilities has been strongly put by Weisz and Tomkins (1996). They build their argument on the preamble to the UN Convention of the Rights of the Child. This states in part that all children have a right to a family environment because the family is the “natural environment” for the growth and well being of children (Weisz & Tomkins, 1996).

This argument however focuses exclusively on the rights of the child without due attention to the family. A Victorian author, Kevin Bain (1998) recently argued an alternative case in the *Medical Journal of Australia*. He proposed that instead of an exclusive focus on what is believed best for the child, there needs to be acknowledgment of the wider impact on the whole family. This requires that the primary consideration be what is in the best interests of the family.

He cites, for example, the work of Turnbull and her colleagues in the states (Turnbull, Brotherson, & Summers, 1982) in which they promote the right to live in the least restrictive environment should apply to all family members not just to those who have a disability. These authors argue, as does Bain, that for many families, continuing to care for their child or young person at home results in their family being required to live in a highly restricted manner.

A strong ideological position on family care also flies in the face of evidence. A significant number of families continue to search for – and find - living arrangements outside the family home for their disabled children. In the US for example, whilst the number of children and young people (up to age 21) in large state MR/DD facilities has decreased overall, the net change between admissions and discharges has increased. So for example in 1998, there were 332 more admissions (in the age range of birth to 21) with most of those, 82.5%, aged between 15-21.

In NSW in a study we conducted in 1995-1996 with 171 families with young children with disabilities and high support needs aged between birth and six years we found that 25% had either sought alternative residential care for their child or considered it might become necessary.

Reasons given for likely placement included if the mother, as main carer, was unable to continue, or the child became larger and harder to manage. The degree to which these circumstances can be avoided by more and better services may be limited. For the 6% of families whose children were already placed out of home, family survival – physically, socially and emotionally – had been at stake.

Recently we completed another study with 84 families with disabled children with high support needs aged 6-13. At our first interview with the families, 6% had taken action to place their child – the same proportion as in our study with younger children. However by 18 months later this proportion had increased to 18%. Overall, around one quarter of the group at both interviews had considered placement. At the same time as those considering placement had increased, we found a significant decrease in those families who had never considered placement from just over two thirds (68%) at first interview to 58% by the time of the second interview.

Clearly there are families who wish to place their children out of home and as the work of Jan Blacher and her colleagues in the US and our studies in Australia also show, once families have considered this possibility it is not a matter of if their child is placed out of home, but when.

A recent study conducted by Stalker and colleagues from the University of Stirling investigated children and young people aged from birth to 19 years with complex support needs in health care settings for long periods in England and Scotland. They found that this age group accounted for over two million 'bed days' in England and 115,000 in Scotland. I think it is clear that despite family care policy and program initiatives, children and young people are



living out of home away from their families – and some for very long periods of time.

This UK study also drew attention to the status of these children – particularly those with a learning disability. The authors questioned are these children ‘looked after’ under the terms of the Children Act 1989 or the Children (Scotland) Act 1995 or not ‘looked after’ but treated as such?

It seems that bureaucrats continue to believe in family care as not only the desired and achievable but also the only alternative for every disabled child or young person. I will touch on the issue of birth family or other family a little later. Now to the second discourse.

### ***Neglectful/ abusive parent discourse***

**Belief that parents no longer able to care for their disabled child are ‘guilty’ of not being able to meet their child’s needs – neglectful/ abusive parent discourse**

Writing over a decade ago in this British context, social workers Sue Trickett and Frances Lee, argued that children with mental handicaps were not being accorded the same rights as other children. They quote several instances of neglect of basic principles such as regular reviews and identification of possibility of reunification or permanent placement out-of-home.

Stalker et al (2003) in their recent England and Scotland study noted that both children with long-term illness and impairment are ‘children in need’ under both Acts and as such are entitled to an assessment of need however they found little evidence that this was happening.

In addition, back in 1989 Trickett and Lee identified a dilemma that remains current today: how to ensure that a child's needs are provided for in a situation where the parents are unable to provide the day-to-day parenting but want to remain involved in decisions concerning their child? These authors cautioned against using care orders in such instances as these are regarded as a punitive measure when parents are themselves asking for alternative arrangements to be made (Trickett & Lee, 1989).

Despite such wise caution, a recent study that we conducted in the NSW Children's Court (1999-2000) provides quantifiable evidence of the over-representation of children with disabilities in care and protection matters before this court. In other words, care orders are used and families with children with disabilities do end up in care and protection proceedings.

Our court study involved a record review of 407 care matters over a nine-month period at two Children's Courts in metropolitan Sydney. Of these 407 cases, 88 (that is, 21.6%) involved children with disabilities or a chronic medical condition. These 88 cases involved 100 children. This figure represents 16% of all children subject to care and protection proceedings in this time period – a much higher proportion than population figures for childhood disability.

Another finding relevant to our discussion today is that while children without disabilities in this study were more likely to receive a custody order, children with disabilities were more likely to be made wards of the state – the government through the director-general then becomes – in loco parentis.

The neglectful/ abusive discourse also appears to infect case management practice. There is anecdotal evidence that case managers 'advise' families to use non-approved means to secure out-of-home placement for their child. For example, refusing to pick up the child from a respite house, or threatening to abuse the child to gain access to the child protection system, which by law must provide safe and secure accommodation to a child or young person in need. In contrast there is no legislation obligating government instrumentalities to provide safe and secure accommodation to disabled children.

One interpretation of the high figures of disabled children in care and protection proceedings is that these figures reflect a systemic response to families no longer able to care for their disabled child rather than neglect or maltreatment per se.

Evidence to support this interpretation comes from our study with the families with children with high support needs aged between 6 and 13 years. In this study we found that families were acutely aware of the shortage of quality placements and, encouraged by professionals, many had put their names on a waiting list even if they currently had no desire to place their child. This action could be thought of as insurance for a possible future when they no longer desired or were unable to provide full-time care for their child. Trying to find an appropriate place for their child was a source of considerable consternation, particularly as many felt that they must start looking at placement options before they were ready.

Ironically, in this study the system 'supporting' families to care for their child at home also provided the impetus for families to take action to place their child out-of-home. Aware of the lack of quality placement options available, coming to realize that their child could not live at home

indefinitely, and prompted by advice from professionals, families put their name on the “departmental database” to ensure a place. Yet, in so doing they risk become constructed differently. Not as families with disabled children but as families unable or unwilling to care for their children, that is, within a neglectful/ abusive discourse at worst or at the very least – a child without a home discourse.

### ***System superiority discourse***

**Belief that systemic responses will provide a safer and more secure future for the disabled child or young person**

This final discourse is perhaps the hardest to ‘unearth’ given the previous two that are more explicit. In the previous two ‘good’ families are those birth families caring for their disabled children at home no matter what. ‘Bad’ families are those who no longer are able or willing to do so.

If the birth family is not ‘up to the task’ then given the ideological commitment to family care, an alternative family must be found to fill the mandate that family care is best for children. In many jurisdictions this has resulted in extremely restricted options for disabled children and young people no longer able to live with their birth family. In valuing only family care the state seeks a replacement family in the form of ‘specialized’ foster care. Building on the principle of permanency planning and seeking to expedite a stable, long-term placement for the child the process moves inexorably toward adoption. Put simply, the substitution of one family for another.

Whilst at first glance this can seem admirable and built on sound developmental principles – that a child’s growth and development requires the secure base of an enduring

relationship – the evidence suggests that few children and young people in the care and protection jurisdiction find long term substitution of another family for their own. Finding enduring and stable new family relationships for disabled children and young people is even more problematic.

The Australian Industry Commission reports on the number of placements for all children and young people who exit from care on a per annum basis. The figures for 2001-02 in NSW show that for those who were in care for less than a year, slightly over one half had only one placement. This is reasonably good news. A different picture confronts us for those children and young people who had been in out-of-home care for longer. In that same year over one third of children and young people who had been in care for longer than 12 months experienced more than one and in some instances many placements. The difficulties for children and young people in establishing enduring relationships in multiple placements are well documented – there is no need to repeat that here.

But what of disabled children and young people and number of placements? Regrettably there is no population data on their experiences. They disappear into the system in some instances via the disability system in others via the care and protection system. Whichever avenue they take – they seem to share an ambiguous status.

Anecdotal evidence from a large Sydney based welfare agency suggests that there is an increasing number of young people presenting to their substitute care services with mild intellectual disability and significant behavioural problems (personal communication, Brother Jeff Kelly, Marist Brothers, 12<sup>th</sup> August, 1999).

This picture of older children and adolescents with mild intellectual disability and significant behaviour difficulties needs to stay with us. It is surprisingly easy to fall into the trap when thinking about disabled children and young people living out of home to focus our attention on younger children and those with high care needs occasioned by their complex physical and /or medical conditions.

Underpinning the systemic superiority discourse is the assumption that an alternative family can be found. This seems to fly in the face of common sense. Families do not 'give up' their disabled children easily. When the difficulties of caring for the child were such that the birth family could no longer provide full-time care is it realistic to assume that another family will not have similar difficulties?

The difficulties some children and young people experience such as a need for intensive medical and therapeutic support or continuous care, or long-term behavioural patterns that include regular violence to themselves or others with little or very slow development, suggests that a roster of carers will be needed. This may not be available in any one family- birth family, adoptive family, or foster family.

In the past, foster care arrangements were generally admitted to be difficult to establish for children with autism, severe disabilities and certain types of challenging behaviours. In NSW this reality remains despite the rhetoric about family care. There are currently over 600 families with disabled children and young people (up to age 18) registered with the government assessment service as being in critical need. Of these 600 families, 125 want out-of-home placement for their child or young person immediately. Without 125 families coming forward

to offer foster care – there are no alternative family placements available – and the families in desperate need continue to sit on the support assessment service waiting list – many have done so for almost two years.

Is it indeed unrealistic to expect an alternative family to manage in a situation where the birth family – typically after years of experience – has been unable to continue? The multiple placements experienced by children and young people in long-term foster care - if this can be found - suggest that the current systemic response – attempting to find an alternative family is seriously misplaced. Continuing belief in the family as the one and only ideal unit (and preferably two heterosexual birth parents) fly in the face of reality for many disabled children and young people.

In conclusion, I have drawn attention to three contradictory discourses currently underpinning the state response to disabled children and young people no longer able to live with their own families. A radical re-evaluation of government policy on disabled children and young people no longer able to live with their own families is long overdue – in NSW at least. While the three pre-eminent discourses – family and community care, neglectful/abusive parents, and systemic superiority – continue to dominate disability and care and protection policy and processes – disabled children and young people no longer able to live with their families will continue to be further disabled by the very systems designed to serve them.

Thank you for your attention. Our website is on this final slide where you can find copies of reports for downloading, practice points sections and also summary of research articles and other resources.

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