

Out-of-Home - Not Out of the Family: Rethinking the Care of Children with Profound Disabilities

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Executive Summary

In New South Wales, Australia, the policy of the State Government Department responsible for people with a disability (*Department of Ageing, Disability and Home Care –DADHC*) states that children with disabilities will have the best outcomes in a family environment. This contrasts with the past practice of placing children with profound disabilities in large institutions soon after birth. This paper seeks to review the current policy direction in light of the views and experiences of families who care for their children with a profound disability. Their views, along with the current literature, suggest that we need to rethink what is the best way to realistically care for children with such disabilities.

There is a growing awareness that

- it is unrealistic that all birth parents will be able to provide permanent care for children with profound disabilities
- the needs of carers and other family members need to be respected and considered, and
- out-of-home care needs to be seen as a valid residential option.

Families of children with profound disabilities were interviewed to obtain their views on DADHC's support system. The parents' experiences were varied, and the needs of their children and their families were unique. Some of the key common themes from the interviews were

- The lack of sufficient respite;
- The need for flexible respite, at the timing of the family; and
- The need for out-of-home options for care.

A review of some other countries' policies on providing service to families with children with profound disabilities indicated that the United Kingdom appears to be leading the field in the area of recognising carers' needs. In the UK, carers are entitled to an assessment of their needs, including a right to appeal that assessment, and the development and implementation of a care plan for the family.

Some of the key recommendations arising from this research and interviews are :

1. Respite care needs to be available in the format that suits the family's individual needs, both in terms of the timing and length of care. If respite does not meet these criteria, it is diminished in value.
2. Out-of-home care needs to be seen as a valid part of the spectrum of services for children with profound disabilities.
3. Staffed group home care may be a desirable residential option for children with profound disabilities: preserving family emotional ties by releasing physical care duties.
4. Carers need a right to an assessment and care plan for the needs of the parents and siblings of children with profound disabilities.
5. It is important that DADHC develop and maintain resources to enable it to provide the services it needs to meet its own goals e.g. that respite care resources, host and shared care families, and group home beds are sufficient to provide the opportunities that parents need.

Background

In New South Wales, Australia, the policy of the State Government department responsible for people with a disability (Department of Disability, Ageing, and Home Care –DADHC) states that children with disabilities will have the best outcomes in a family environment. This contrasts with the past practice of placing children with profound disabilities in large institutions soon after birth. This paper seeks to review the current policy direction in light of the views and experiences of families who care for their children with a profound disability. Their views, along with the current literature, suggest that we need to rethink what is the best way to realistically care for children with such disabilities.

Methodology

Policies and practices for children with profound disabilities were examined for Australia (New South Wales), Canada, the United States, and the United Kingdom. Existing research papers on caring for children with profound disabilities were reviewed. The full bibliography is appended at the end of this paper.

The families of four children with profound disabilities living in the Hunter region of New South Wales were interviewed at length about their experience of caring for their children and their views about alternative methods of caring from their children.

Policy

The NSW government's policy on caring for children with disabilities is stated in the Department of Ageing, Disability and Home Care's (DADHC) policy document "Living in the Community: Putting Children First". The Ombudsman summarised the policy as:

- Children and young people with disabilities will have the best outcomes if they are brought up in the community in a family environment, preferably their own.
- They should have the same access to mainstream services as other families in the community.
- Where their needs cannot be met through mainstream services, these needs should be met through specialist disability services.
- For children and young people with disabilities who cannot live with their families, family type care is the preferred option. (NSW Ombudsman, 2004, p. 2)

The policy states that family-based care is the best model of care for children under 12 years. It goes on to say that families with a child with a disability should have access to services that reflect assessed needs, and a certainty about service provision over the short, medium, and long terms. The primary strategies for achieving the policy principles include early intervention and prevention, and building capacities of families and communities.

The spectrum of care for the implementation of this policy for families with children and young people with disabilities includes:

- Care by the biological family (parents and other family members)
- Case management
- Emergency services
- Home care supports
- Respite care
- Out-of-home care

An investigation into DADHC by the New South Wales Ombudsman in 2003, found that the "implementation of its children's policy had been characterised by:

- A poor implementation strategy
- Lack of clarity about DADHC's role in supporting families in crisis
- Uncertainty about which sections within the DADHC had responsibility for providing such support
- Inadequate guidance to staff about how to implement the policy
- An inadequate operational framework to underpin the policy
- Lack of clarity about the respective responsibilities of DADHC and the Department of Community Services
- Conflict between policy requirements; and

- Subsequent confusion in practice.

The Ombudsman also found that for families seeking support to care for children and young people with disabilities there was:

- Lack of clarity about how to obtain access to services
- No clearly defined or consistent decision making processes about access to services
- A fragmented service system for those able to access it
- Poor co-ordination of services
- No clearly defined avenue for review and appeal where services were denied or considered inadequate by the family.

Families who care for children and young people with disabilities already face significant stress. The result of the DADHC's ineffective implementation of its policy for children and young people with a disability was that this stress was unduly aggravated." (NSW Ombudsman 2004, p.4)

The New South Wales Ombudsman investigation confirmed that "staff were unclear about how to implement the policy...put their own interpretations on what the policy meant...[and] This meant that some families in crisis received a service, while others in similar circumstances did not." (NSW Ombudsman 2004, p.5)

DADHC's policy lacks any significant focus on out-of-home placement as a method of care. This sets the stage for the lack of funding and resource development that is required to effect that option. Does the lack of funding for implementation of a theoretical policy option create a new policy of reality?

The policy does make provision for the Regional Director to approve the placement of any child under 12 years of age in DADHC or DADHC-funded group home accommodation. It is interesting to note that the decision-maker is a Regional Director, implying that the decision is not one based on the needs of the child or family, but is one of money and whether or not DADHC is prepared to pay for the placement.

Children with Profound Disabilities

DADHC's policy does not differentiate guidelines and strategies based on the severity of the disability.

"One of the shortcomings of the policy is the lack of a separate definition and category for children with complex needs. (Family A)

The policy itself is okay, but there should be a "but" in there." (Family B)

Some parents of children with profound disabilities have been asking that their children be placed in out-of-home care. DADHC's expectation that children and young people with profound disabilities will be cared for in home environments may be unrealistic for all cases.

This paper focuses on the care for children with profound disabilities. It looks at some of the current research around out-of-home care for children with profound disabilities, and provides some first hand accounts from four families who have been asking for out-of-home care for their children with profound disabilities.

The Australian Bureau of Statistics defines profound disability as:

- always needing assistance in self care activities such as bathing or showering, dressing, eating;
- always needing mobility assistance such as getting to and moving around when away from the home, and moving about in the home; and
- inability to communicate: cannot understand family and friends, and cannot be understood by family and friends.

Children with profound disabilities may require interventions such as tube feeding, 24 hour nappies, use of hoists and other mobility aids. The children may have serious intellectual deficits, lack of attachment, multiple medical needs, and mobility without a sense of danger. Each child with high and complex needs is an individual, and it is important that it is acknowledged that every child with

complex needs will not automatically fit into a pre-set program or formula for care. Each child's needs change over time, and the child's needs or challenges may increase with their age and size. Each child and family will need an individual plan that includes a consideration of the full spectrum of services. DADHC's policy provides for such a plan, but the reality of finding some of these services, and implementing them, can be a nightmare or non-existent.

Definition and Scope of the Impact

The Australian Bureau of Statistics 2003 survey found that, throughout Australia, 4% of children aged 0-4 have a profound or severe core-activity limitation, 6.5% for males aged 5-14 years, and 3.3% for females aged 5-14. (ABS 2004).

In 1993, there were an estimated 63,500 Australian children between the ages of 5 and 14 years of age with a severe or profound handicap. (Llewellyn in Bain, 1998, p. 599)

Out-of-home Care

The view that all children need to be raised in a home environment is a relatively new policy. During most of the twentieth century, families were encouraged to place children with profound disabilities in institutions. Research on child development within these settings indicated poor outcomes, and a new movement of de-institutionalisation began during the 1980's. Just as institutionalisation of all children with disabilities was wrong in the past, the current view that all children with disabilities must live at home may be a doctrinaire and unrealistic position for the 21st century. (Bain 1998)

There is a significant disparity between the rhetoric that "all children belong with families" and the reality. (U of Minnesota 2000) While the New South Wales' policy paper does not completely exclude out-of-home care; the implementation of that policy – through lack of funding and alternative resource development – effectively creates a narrower spectrum of services. Civil servants who may see that institutions are out of vogue, are adopting a strong "gate keeping" role to minimise any divergence from the two approved models – birth or substitute family. (Bain 1998)

"One Queensland agency which implemented faithfully the total movement of children with high medical and physical support needs back into birth family settings after a period of institutionalisation reported that the outcome [for the family] was often "harsh". (Bain 1998, p.598)

Research in the child protection field in Australia indicates that foster care for children and young adults with higher support needs is hard to find, often hard to maintain and not necessarily the preferred option of the young people concerned. Reports such as these should provide a caution against adopting a one for all policy of foster or shared family care. It may be the case that some children and young people and their families will do better within other models of residential care. (Llewellyn, 1999)

The National Alliance of Young People in Nursing Homes (YPINH), an advocacy group lobbying against the inappropriate placement of young people in nursing homes, cautions against adopting policy stands that exclude residential options for individuals and families. Recommendation #5.6 of their submission to the Senate Community Affairs Committee Inquiry into Aged Care in August 2004, states:

"That a range of sustainable accommodation and support options be developed in consultation with YPINH and their families, as well as members of all stakeholder groups. There is no one solution to this complex issue of accommodation and support. 'Options on the spectrum' need to be made available to young people with high/complex care needs....maintaining nursing homes as one option on the spectrum is important for several reasons....This is especially important in rural areas where critical mass may be low and services more limited." (YPINH, 2004, p.28)

While the YPINH is generally speaking about young adults rather than children, the concept is similar: that residential placement is a valid service option for some children and young people with profound disabilities and complex medical needs and their families.

Care by the Biological Family

The basic responsibility and underpinning of all care for children is their biological parents. Parents are responsible for various care-giving functions – ranging from the basics of food, shelter and clothing to transportation, recreation and nurturance. In the process of this care-giving role, parents provide intermittent care for ill or injured children, and can become active in advocating for their specific child's needs or children in general. So it is natural that society would look first to parents to provide for the needs of children and youth with disabilities. Governments are also very cost-conscious and parental care may be the most cost-effective way to care for people with disabilities.

When a child with a profound disability is born, the parents of that child automatically become career carers. The family home becomes a residential placement, around which a number of services and service providers are centred. Regardless of the number of assisting services, the parents are left with numerous care-giving tasks which require the combined professional skills of nurses, teachers, therapists and administrators. They manage complex intra and extra family relationships, monitor children's conditions, perform custodial, therapeutic and medical tasks, schedule appointments, act as advocates and more... (Roehrer Institute, 2000)

Career carer is not a profession that these parents have chosen or trained for. It is a profession without an end – no daily or weekly maximum number of hours, no guaranteed pension date. It is a profession without pay, without the protection of occupational health and safety laws or unionised benefits.

“As a parent, I was unable to obtain a hoist to lift my son. But, when Home Care was approved to provide support, they were not permitted to start providing service until a hoist had been installed, in order to meet health and safety standards. (Family C)

It is a profession without the rights, privileges, and prerogatives that come along with career status. (Raina et al 2004) These parents, seemingly chosen at random, have varying degrees of competence in their new roles, and it would be unrealistic to assume that every family that inherits these roles will be able to thrive and excel in performing them. A policy that depends on the skills of the family for care giving and advocacy for the child is inherently uneven in service provision. (Llewellyn, 1999)

Families of children with complex needs frequently confirm this role:

“It wasn't my choice to have a carer career. ...It's against my nature to complain.”(Family D)

Yet this same person, faced with the possibility of not finding a school that would take her child, simply sat in the school office until they agreed to register him. Whatever skills and training the parents did not have prior to the birth of their child with profound disabilities, had to be learned, and learned fast.

It is unclear whether government enthusiasm for family care is driven by a philosophical belief that families are the best caregivers, or by the bottom line - a financial consideration – given that it is generally perceived that family care is a cheaper way to care for those who would otherwise require expensive residential services (Llewellyn 1999). If one looks strictly at the financial considerations, it is not clear whether the cost-benefit comparison includes items such as:

- The lost opportunities and income of full-time carers who would otherwise be employed in the workplace

“I'm a registered nurse, and our community needs nurses, but I have to regularly turn down shifts, as there is a limit to the number of hours and money that I can earn without losing my carer pension, which provides critical funding for nappies, medicines, and other equipment.” (Family C)

- The cost of the health care for the carers and their families, due to illnesses directly related to their care giving role

“I have arthritis in my knees and a bad back from kneeling and lifting when giving care.”(Family B)

Other parents reported psychological effects that required medical and advocacy interventions.

It may be important to note that parental care in the family home, supported by case management, homecare, and/or respite services is not a true family setting. “The family home itself becomes an

alternative form of placement. System interventions mimic placement activities by coordinating arrangements that focus around the family home as a place.” (University of Minnesota 2000, p.4) It is no wonder that the impact upon the entire family is significant – try and envision your family home with daily workers coming into the home, timetables of appointments to coordinate and attend, and a dependency on others who may or may not be competent or dependable or agreeable.

Case Management

DADHC does provide case managers and service co-ordination services. These are based on a planning paradigm centred on individual service plans that are made and updated annually.

“The case manager might be able to create overall global service arrangements, but the day to day “fine tuning” is left for the parents: providing transportation when the bus service fails, picking up children when they are too sick to be in school or the respite home, re-scheduling appointments around sick children or busy doctors.” (Family A)

While the case managers were often encouraging and acknowledging, their ongoing effectiveness in helping was lacking at times.

“My case manager said “you’re doing a great job, call if you’re desperate.” (Family C)

Parents of children with disabilities sometimes find themselves competing against one another for scarce resources, and comparing the services that other parents receive to those that their family gets. Some parents consider that the effectiveness of the individual case manager plays a large part in the services that each individual family receives.

“The squeaky wheel gets the oil.” (Family D).

Emergency Services

DADHC policy states that one of its immediate priority initiatives is to provide emergency services to caregivers. (DADHC Future Directions August 2004) However, workers could not always be counted on to provide emergency services for the parents when needed.

“I called once for a day’s help when I was sick – only to be asked whether I could find a friend or family member. I ended up just managing by myself.” (Family A)

“I was on the brink of a nervous breakdown, and called for emergency help that never came. Thankfully, my son, who had been going through a particularly difficult phase, settled down, and I recovered – no thanks to DADHC.” (Family D)

Sometimes DADHC relied on the biological parents to provide emergency service for their children with profound disabilities, even when the family had left the child in respite or permanent care. Departmental staff would call to report that the child had not been picked up at school, was sick in the respite home, or that DADHC was unable to find a residential placement for him – with the assumption that the parent would be prepared to fill the gap that DADHC could not. So, while DADHC states that one of its goals is to provide respite and other emergency services to parents, the reality is that parents were sometimes expected to provide emergency services for DADHC.

Home Care

One of the most common supports that families with disabilities are offered are home care services. This can be housekeeping services, personal care services, in-home respite, or a combination of these three.

All parents interviewed for this paper expressed mixed thoughts and emotions over homecare.

“You can’t live with it, and you can’t live without it.” (Family A)

Every parent interviewed had some positive experiences with homecare, and some of the workers that came to help their family:

“The best worker would consistently bring back my son late from the respite activity because they were having so much fun. My best gauge on the quality of care that the respite worker provided came from my other children’s views on the care giving when we were gone.” (Family D)

I could tell what workers were good by how much they knew about my child, and whether they could recount what had happened during the respite period.” (Family B)

One family who lived in a rural area was lucky to have 2 homecare workers who have provided consistent care over four years, and who have become like extended family.

Parents expressed the most discomfort at the beginning of homecare services – when they were first asked to open their homes to strangers, especially early in the morning before everyone was dressed and socially presentable.

It is interesting to note that while DADHC expects that biological parents will be able to handle the daily rigours of the physical care for children with severe disabilities, the homecare workers are often rotated to ensure that each is not burnt-out by the task.

“No homecare worker could work two consecutive days, so our family had 8 different workers over a fortnight period.” (Family D)

“The homecare workers are used to working with frail elderly people, and were not sufficiently trained and skilled to care for children with severe disabilities. So we had to switch to a service that specialized in care for people with disabilities to provide the personal care.” (Family C)

Most families experience a number of different workers over time – some good and some not so good. Worker turnover and individual worker competence were often cited as concerns.

Part of the challenge of having homecare was the added dimension, sometimes expressed as the added stress, of dealing with the people who arrived to provide that care.

“Some of the workers were great – those that “loved my son to bits”, others were “rough” when handling the child, didn’t respect the family’s boundaries, or had their own issues that they downloaded onto us.” (Family A)

Parents expressed their turmoil, a conflict between the need for help and not wanting to be perceived as ungrateful or excessively demanding. As a result, some parents expressed their willingness to accept the service as provided, feeling awkward about demanding anything from the workers.

“I felt I had to accept whoever showed up at their door to provide respite, regardless of their skills.” (Family A)

Out-of-home Respite

Another key service provided to parents of children with disabilities is out-of-home respite. Overnight respite is usually provided in staffed group homes.

All parents who were interviewed for this paper expressed their need for out-of-home respite. Each parent used the time in different ways. Some parents, whose children were particularly active and noisy at night, used the time to catch up on physical rest. Other parents used the time to do things with the rest of the family.

“I try and fit my whole life into that week of respite – go out for dinner with my husband three times, take my other children to movies and shopping, and on trips. I would be exhausted when the week was over.” (Family C)

Every parent stressed the importance of being able to arrange respite when their family needed it. Each family was different – the rural family wanted one week blocks due to the time and distance to the respite home. Another family wanted respite for every school holiday due to the stress and demands of continual 24-hour care. All families said that it was important that respite was available when they needed it. Parents expressed the importance of being able to take a holiday from care giving, citing the need for an annual 3-4 week block (without decreasing the number of other respite days throughout the year, as is the current DADHC practice).

Host Families

Host families is a practice in which a child with a profound disability is placed with another non-biological family unit. The system is similar to foster care, with the primary difference being the biological parents do not relinquish their legal custody. Like foster care, the theory is to provide an alternative, stable family home for the child. And like foster care, host family situations may change and evolve, resulting in multiple placements for the child with disabilities over time.

The concept of host families arises from the notion that every family unit has different capacities and resources, and that some host families may be better equipped than the natural family to cope with children with profound disabilities and the constant interventions of health and social workers. Not every biological family is willing to accept the intrusion, and function as a placement for a child with profound disabilities. Not every biological parent has the skills or abilities to care for a child with a profound disability, and these parents may be willing to have another family provide an alternative home environment.

In other circumstances, where the natural family has adequate or above average skills and resources, it is perplexing how another family could do what the loving birth family could not. (U of Minnesota 2000):

“I found it insulting that DADHC considered that a host family could handle it better than us.(Family A)

A host family would have been inappropriate for my son, because he was unable to bond with others. So eventually, the host family would have burnt out.(Family A)

How can a host family be a permanent solution? The host family will experience the same sleepless nights, and it will eventually wear them down, too.(Family B)

Will DADHC provide any more supports and respite for the host family than for us? And if they don't, how will that host family cope?”(Family A)

None of the parents interviewed expressed any positive comments about the concept of host family placement, or any interest in this model of care for their child.

Shared Care

Two of the four families interviewed indicated that shared care appeared to be a best option, and both would have chosen that option if it had been offered and available to them.

Shared care is an arrangement, organized through DADHC, where the care of a child with a profound disability alternates between the biological family and another family unit. The second family unit is chosen and supported by DADHC, in a process similar to that for foster families. The time spent by the child in either home can be negotiated. For example, one child with a profound disability may spend alternate weeks at the biological and shared care home, while a child with a profound disability from a different family may spend weekends at a shared care home. DADHC provides the shared care parents with financial compensation, training, and other supports. At the time of writing, shared care is a relatively new approach, primarily individualized and child-centred.

Although biological families expressed a reluctance to consider their children being raised in the foster system due to concerns over the abuses and alleged abuses of children in foster care, these same

parents did not indicate such reservations with a shared care model. Parents indicated that they believed that they would be involved in the selection of the family that would share the care, and that the regular contact and involvement of the family of origin would ensure that the child would be safe. It was very difficult to identify a parent who had experienced shared care, as the concept is much more of a theory than a reality at this time.

“Recruitment of alternate families holds much untapped potential.” (University of Minnesota, 2000, p7)

Staffed Group Care

The parents of children with profound disabilities who were interviewed have each asked for their child to be taken into full time residential care. The parents voiced opinions of many other parents of children with profound disabilities who have been the full time career carers, who have co-ordinated the home-based services, and who have lobbied on behalf of their children with profound disabilities. These parents have had homecare services and respite. Their homes have been the child’s placement venue; their spouses and other children have experienced a family life centred on the primacy of the child with the profound disability. And now these parents are asking for an opportunity to relinquish their roles as nurses, administrators and therapists to staff, and to be given an opportunity to remain the child’s sole parents while their children reside in staffed group homes.

All of the families interviewed indicated a degree of comfort with the staffed group care model, and a propensity to see this as an agreeable residential solution for children with profound disabilities. One reason for this level of comfort may be that overnight respite care is provided in this model, and so it is a familiar experience. And, while their experiences of respite care in staffed model settings included both negative and positive incidents, the overall consensus was that it was a safe place for children with profound disabilities to be.

Parents liked the concept of a staffed model because the shift work would ensure that people working in the home would have rest, and opportunities to rejuvenate, thereby minimising burnout. The night shift staff would be awake and regularly checking on the child, providing an even higher level of night care than a biological parent or parent-model home (host family or shared care) could provide on a regular basis. Staff would regularly have opportunities to have a good night’s sleep, and could take a break after 8 hours, returning refreshed. Multiple staff working in any home would act as an internal monitoring mechanism and check and balance for the care of the children. Host family programs do not have these important characteristics and internal accountability mechanisms.

Staffed group care “has the potential to provide long-term security, trained staff, and greater authority to birth parents to influence decisions about the child’s welfare than does foster care. Rostered staff carers resist “burnout”, and often develop a familiarity and attachment to the child, even when it is not strongly returned.” (Bain, 1998, p599) Staffed group care also has the potential to provide a permanent home for the residents, from childhood through into the adult years.

A 1993 US study found that families who placed their child in a residential facility were much more likely to continue a high level of contact with their child than did previous generations. (U of Minnesota 2000) Parents can continue providing parental love and guidance, while letting the staff take care of the child’s medical needs. In contrast to host family or shared care situations, the biological family unit can be maintained intact, and the child is not torn between two sets of parents.

In both families interviewed where the child had been placed in staffed group care, the families continued regular contact with their child. Further, both reported that the contact increased in quality, and centred around sharing love, play, and affection, rather than meeting the physical needs of the child’s body. It is important to note that “placement out of the home need not mean placement out of the family” (Llewellyn, 1999, p. 10), and in fact, it can foster the reverse.

Permanency Planning

It is interesting to note that permanency planning is not specifically mentioned in DADHC’s policy or standards regarding children with disabilities. The term first appears in DADHC’s guidelines regarding out-of-home placements.

“A permanency plan needs to be drawn up from the day that a diagnosis of a profound disability has been made.” (Family A)

Every parent interviewed expressed concern over the uncertainty of future funding and supports for their child. All of the parents interviewed anticipated that their child would end up in a staffed group home as an adult, and questioned a policy that arbitrarily sets that transition date at 18 years of age. Some parents felt that the child would make the transition better at an earlier age, and that the adult service system would be more likely to make room for a child who was already in full time care.

One parent pointed out that a host family is not a permanent solution, and therefore is not preferable to a staffed group home placement, with continuing family involvement.

Another parent pointed out that the biological family is also not a permanent solution.

“Parents of children without disabilities can expect that their children will leave home and their parental responsibilities will end at about 18 years of age. Caregivers of elderly parents who are declining in health, can expect that those parents will be accepted into a nursing home. Caregivers of the elderly can submit an application for a nursing home spot, and can be assured that that application will be processed, placed on the waiting list, and a place found for that elderly person in due course. For parents of children with severe disabilities, there is no such end in sight.” (Family C)

As parents of children with profound disabilities are left without a right to an out-of-home option, some parents are then left with the only other action they deem possible: unilaterally leaving the child in a respite home.

“We are well aware that a child must be left at respite in order to avoid being charged with abandonment.” (Family D)

This action has numerous negative impacts, including “blocking” a respite bed that other families may need, and traumatising both the child and the biological family due to the lack of transition planning.

It has been argued that the development of residential options encourages use of those facilities – a kind of “build it and they will come” view. Every parent that was interviewed for this paper expressed extreme angst over the decision to request that DADHC accept their child for residential care.

*“No family **wants** their child to live away from home”. (Family B)*

Parents reported listening to various opinions of family and friends – ranging from an encouragement to place the child to a critical judgement of “how could you do that, he’s your baby?” For a parent, the decision to ask for residential care is an extremely difficult and emotional one, and it is unlikely that having more out-of-home residential options and resources would encourage parents to give up their children with profound disabilities. What building residential services **will** do, is provide parents of children with profound disabilities with more options and emergency services.

Carer Needs

Over the last few years, the notion of carer needs has come to consciousness. As recently as October of 2004, the government of Western Australia passed the Carer Recognition Bill to recognize “the role of carers in the community, to provide a mechanism for the involvement of carers in the provision of services that impact on the carer and the role of carers.” (National Council on Intellectual Disability, 2004) This bill, however, is not as comprehensive as the Carers and Disabled Children Act 2000 in the United Kingdom (see below).

One of the fundamental underpinnings of the policy for children with disabilities is based upon their right to live in the least restrictive environment. Increasingly, the “concept of least restriction should be considered in light of the needs of each family member. Placing many severely handicapped children and youth in the least restrictive environment of their families results in their family being required to live in a highly restrictive manner.” (Bain 1998, p. 599)

In New South Wales, the absence of the recognition of carer rights has fostered feelings of powerlessness.

“We, as parents, have no right to services at all.” (Family A)

“We need to have a right to an option – to be able to put your name on a waiting list, so that there is a time and an end in sight.” (Family C)

Intertwined with the notion of carers’ rights, are the rights of the siblings of children with profound disabilities. Family units are a social system – envision it as a whole unit of one. The time and energy spent caring for the physical needs of the child with a profound disability subtracts from that finite number one, leaving less time for other family members: the other parent and the siblings. Several parents expressed concerns over the effects of unequal time commitments for their children:

“My other son was neglected, and he still has problems. He was 2 ½ years old when B was born. He was friendly, happy go lucky. We had to leave him with many different people while we were in the hospital. Once B came, we just didn’t have enough time for him any more.” (Family B)

“The other children have suffered. His sisters won’t go out with him, so we can’t go anywhere as a family. The younger child is picking up J’s bad habits.” (Family D)

“I’ve heard that 85% of marriages with children with severe disabilities end in divorce.” (Family A)

DADHC’s policy is quite clear that where the needs of the child with the disability and the needs of the family are incompatible, the needs of the child with the disability is paramount. (Children’s Standards in Action 2004) This is reflected in the absence of any case worker that would represent and support the balance of the family. Yet, given that the family is a single social unit, any unmet needs of the balance of the family will ultimately impact upon the child with the disability, and it may be a short-sighted strategy to relegate family needs to a lesser priority.

United Kingdom

It appears that legislation and policy in the United Kingdom leads the way in regards to carers rights. The first legislation there concerning carers rights dates back to 1995, and was revised and improved in 2000. The key difference that this legislation provides is a right of carers to an assessment of their ability to care. The legislation includes provision for appeals of that assessment. The assessment forms the basis for a care plan for the carer, and the provision of services to the carer. “The practice guidance encourages local authority staff to think creatively and flexibly” [about what services to provide for the carer]. (Policy Briefing, 2000, p.4)

The carer assessment should

- “focus on a list of outcomes the carer wants to see [e.g. a good night’s sleep]
- be a carer centred process
- look at the impact of the whole caring situation
- consider the level of choice a carer has in undertaking caring tasks
- consider health and safety issues for the carer
- look at what support carers might need to manage daily routines
- look at what opportunities the carer has to maintain social contact, employment, etc.” (Policy briefing 2000, p.11)

Another unique feature of the carer system in the United Kingdom is the voucher system for respite care. This concept is still in the early stages of implementation, and there are few studies available on its effectiveness. The theory is that carers will be given vouchers to enable the carer to choose their respite carer and the timing of respite. The theory is that this system will provide carers with greater freedom to choose respite how, when and where the birth family needs it. One concern that has been expressed about the voucher system, is whether the respite services would be developed and available, or whether parents would be left holding a piece of paper that entitles them to a service that just isn’t there.

“All decisions to place a child or young person in residential placement are based on multi-disciplinary/multi-agency assessments of the child’s needs.” (United Kingdom Department of Health,

Disabled Child, p.32). This is an interesting difference from the DADHC's policy that the Regional Director must approve the placement of any child under 12 years of age in DADHC or DADHC-funded group home accommodation. (DADHC, Supporting Children with a disability and their families: out-of-home placements, 2004) The United Kingdom's policy clearly places the onus on a team of social workers, who will decide the placement based on the child's needs. The New South Wales guidelines puts the decision-maker as a regional director, implying that the decision is not one based on needs or social work considerations, but is one of money and whether or not DADHC is prepared to pay for the placement.

Research

It has been noted that research into the field of residential care for children with profound disabilities is lacking, and that this lack of data results in inaction or inappropriate action on the part of government policy-makers.

The original movement from institutionalisation was based on outcome studies of children who had been raised in large institutions and who did not have frequent or quality contact with their birth families. There are few studies into outcomes for children with severe disabilities who have been housed in staffed group homes or host families or shared care situations, and who have continued to be nurtured emotionally from ongoing contact with their birth families.

A recent investigation by the New South Wales Ombudsman determined that DADHC was unable to provide statistics on the numbers of children with profound disabilities that were in voluntary care, and where they resided, and what quality of care they were receiving. (NSW Ombudsman 2004)

"Data collection not only identifies trends, it steers them. By asking questions at a national level, agendas are set and priorities identified. What is asked, and what is not, tells much about what is considered important in developing services for people with disabilities." (U of Minnesota, p.8)

"Independent evaluations of successful foster care and rostered staff programs are needed, with results made available to all. These should examine the priorities not just of the planners (minimal placement breakdowns, placement avoidance, and service cost reduction), but also of families (family satisfaction, strengthening of birth family links, and quality of care)." (Bain, 1998, p.600) This research needs to focus on the outcomes that are critical for the children and young people, for their families, and for the community. (Llewellyn 1999)

Conclusions

DADHC's policy statement about children with disabilities does make room for a full spectrum of supports. As noted in the Ombudsman's report, it is the implementation of the policy that is lacking.

Some families of children with profound disabilities have clearly said that it is unrealistic for DADHC to expect the homes of all birth parents of children with profound disabilities to be the permanent placement for those children.

Research and interviews of parents of children with profound disabilities indicate the following:

1. Respite care needs to be available in the format that suits the family's individual needs, both in terms of the timing and length of care. If respite does not meet these criteria, it is diminished in value.
2. Out-of-home care needs to be seen as a valid and essential part of the spectrum of services for children with profound disabilities
3. Staffed group home care may be a desirable residential option for children with profound disabilities: preserving family emotional ties by releasing physical care duties
4. Carers need a right to an assessment and care plan for the needs of the parents and siblings of children with profound disabilities

5. It is important that DADHC develop and maintain resources to enable it to provide the services it needs to meet its own goals e.g. that respite care resources, host and shared care families, and group home beds are sufficient to provide the opportunities that parents need.

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