The long term care of children with disabilities

Is family the only way?

Kevin Bain

Some families need to place their disabled child in long term out of home care, due to a high care burden. Foster family care is increasingly the only option available. While published research is sparse, there is evidence that rostered staff models of care are more appropriate for some children, and the potential gains from family care are overstated. Questions are raised about foster care successes overseas and locally, particularly as care options are restricted to in home support or alternative family models. Rostered staff models can promote a child's involvement with the birth family, and should be developed further. Planners need to foster diversity, which allows flexibility and promises new knowledge.

The burden of care of children with disabilities and high support needs may be so demanding that parents seek a separate living situation for their child. Close attention is necessary for children with certain medical conditions, requiring 'on call' support around the clock. Some other children have long term behaviours of violence towards self or others, destruction of clothes or household effects, screeching and noise at all hours, eating inedibles, smearing faeces, or absconding. The notion that consistent 'training' through school programs, psychological interventions, or behaviour modelling will lead to qualitative improvement is often just a hope: the future may be one of slow development, or regression. Unless they have unusual personalities, or have extraordinary resources to draw on, these families may expect social relationships to unravel, with chronic stress or family breakup the result. A study of 171 families in NSW (Llewellyn et al, 1996) found three factors which influenced the parents' decision to seek out of home care:

- the level of congruence in family life between the needs of the child with a disability and the needs of other family members;
- the degree to which the child with a disability is integrated into everyday family life and the community; and
- the level of parent concern about the effect of the child with a disability on their brothers and sisters.

Where out of home care becomes unavoidable, foster care is increasingly the care model pursued by state government child welfare departments. The claim is that departments and agencies can find and support an alternative family to successfully incorporate the child and provide improved developmental prospects. Adoption by the foster family or another substitute family is the goal in some jurisdictions, although this is not often made explicit.

In Victoria, 'research' is commonly cited to justify the Family Options program as the universal answer, but this research is not presented to parents or other interested parties through departmental publications or professional journals. In fact, the narrow range of options available to families seeking out-of-home care for their children is not supported by advocacy groups, academics, direct care staff, professionals and even respite and foster care agencies. This has not stopped implementation, which continues apace.

As part of a recent study tour to South East Michigan to examine this subject, I reviewed the literature on residential care for children with disabilities, and found a substantial research interest in placement predictors and prevention, but few studies of care models either from US or Australian sources. This is probably not surprising, given existing policy priorities. Fortunately, the gap is largely filled by a number of thoughtful writings from Jan Blacher of the University of California, Riverside, which explore placement alternatives, and promote a more pragmatic approach to non-family care models. The publicly available research is

---

***Kevin Bain** is the parent of an 11 year old boy, living in a Department of Human Services (Vic) respite house. He is a former board member of intellectual disability advocacy bodies in Victoria, and he was awarded a travelling fellowship from the Rosemary F Dybwad International Fellowship Trust Inc in 1997 to visit South East Michigan to review accommodation and support provided to young children with disabilities.*
Contact: Tel (03) 9290 1845 (BH) OR email: kevinbain@yahoo.com.au

mainly in the form of case studies of programs (including reports from the programs themselves), surveys of parents, staff or professionals, and a very small number of longitudinal studies of service users.

A Freedom of Information request I placed on the Victorian Department of Human Services (DHS) in September 1997 also provided some supplementary information, including a 1993 evaluation of Melanie's Program, a small NSW service which specialises in foster care of children with disabilities.

As well as reviewing the research, this article also presents a case for a more active consideration of alternatives such as small group homes with rostered staff.

FAMILY AND NON-FAMILY MODELS

For the birth parents, the foster care approach is puzzling, as they would have already tried family-based solutions – respite services, in home modifications, behavioural intervention, and exhaustive meetings to conduct assessments, and review motivations and parenting skills. The prospect of an alternative family raises a whole series of questions for parents who are not negligent, abusive, or deficient in skills, and may have successfully raised other children.

- Does the department and its agents have the ability to do this successfully?
- Are we the guinea pigs for the latest mood swing in policy?
- If parents, who have tried all the options over many years to keep the child at home, still can't find a way to do it, how can someone else?
- How can the bonds between my family and my child be strengthened with another family in the middle?
- How much say will I have and whose wishes prevail?
- Does it mean turning an alternative family home into a mini-gaol, confining the child, de-socialising the other family members, creating a repressed and depressing living situation for the other children, in the name of a desirable 'model'?

Prima facie, one might expect that the most effective arrangements for children and their families might vary according to each case. For instance, children who do not bond easily to another person are often considered the most likely candidates for a failed foster placement. However, 'research into residential care for autistic individuals is virtually non-existent' (Schopler & Van Bourgandien, 1990, p 289). In the US, there is a 'deep and enduring skepticism' about group-care settings for children and youths, and a

> ... belief that true system reform will not occur as long as a 'placement' philosophy dominates service thinking. Hence any attempts to examine group child care seriously (other than perhaps documenting the abuses within it) are resisted for fear of promoting the service over other more family-centred and placement preventative alternatives. One consequence... is that money for pilot testing of new residential models... has been extremely limited. (Whittaker & Pfeiffer, 1994, p 584)

However, various US studies contradict the view that group care for children and youth is counterproductive and even intrinsically abusive (Ainsworth, 1997, p 14).

Where out of home care becomes unavoidable, foster care is increasingly the care model pursued by state government child welfare departments.

The research agenda is not set in a policy vacuum, of course. In the Australian child welfare field, it has been claimed that a recycling of beliefs and fashions about long term care for children occurs regularly, and alternates between support for natural families, support for foster families and group solutions. Each generation discovers anew the reasons why the dominant solution espoused by the previous generation has not worked well for some children and families (Russell, 1992, p 21). The ideas of permanency planning through family care which have become important in child welfare in the US and Australia are also influential in long term care for children with disabilities, who are seen as a special case, within the mainstream of policy. Although it was anticipated in 1994 that in Australia 'congregate care, at least in the form of more accessible respite care is again appearing on the agenda' (Cant & Hand, 1994, p 18), this does not seem correct for Victoria or South Australia where policy favours substitute family models, and demand is being channelled towards them, rather than to respite houses. As well as being a popular form of respite, the houses are an opportunity for desperate parents to gain a foothold on fulltime out of home care, and planners have shown concern in the past at the leverage this may give parents.

Parents want options, and long term care decisions made on the merits of each case. This would include consideration of a rostered staff model of care. The rostered staff model (or 'group home') provides reliability, trained staff, professional protocols, and protection from burnout through exhaustion. Because it is not someone else's home it gives potential accountability to parents on home modifications, clothes, diet, and sleeptimes. Other factors drive current policy, however, with ideology and cost constraints ruling out this option (Mason, 1996).

BEHAVIOUR MODELLING AND TRAINING

What do we know about whether foster care is the appropriate model for children with the more extreme behaviours? A major government and professional panel in the US reviewed the Treatment of Destructive Behaviours in Persons with Developmental Disabilities during 1988-89, and issued a Consensus Statement (National Institutes of Health, 1990, p 403). The more extreme cases of self-injurious or aggressive behaviour were defined as repeated self-inflicted, nonaccidental injuries producing bleeding, protruding and broken bones and other permanent tissue damage, eye gouging or poking leading to blindness, and the swallowing of dangerous substances or physical objects. The Panel estimated that 20,000-25,000 individuals behaved in this way. (Assuming a similar incidence here, Australians so afflicted would number from 1,350 to 1,700 on a *pro rata* population basis.)

The Consensus Statement (National Institutes of Health, 1990) noted that treatment is difficult, often controversial, and with serious social and personal consequences. Although persons with severe to profound mental retardation were more likely to be afflicted, the behaviour rather than the level of impairment was the trigger for special care, with 24-hour observation, supervision, and treatment sometimes essential for safety reasons. While favourably inclined towards family care for most disabled children, a South Australian study also questioned the extent to which adequate support can be provided to families, when the child displays extreme behaviours (Kelly et al, 1995, p 84). The provision of intensive support to the child in a family situation radically changes the living patterns for all family members.

It is clear from Departmental and agency officials in Victoria that a major reason for foster placement is to model a more normal environment, compared to a group home. However, the issue of a supposedly dysfunctional environment does not appear to rate as importantly in the successful programs operating in South East Michigan, where many of the foster homes have a number of disabled children – in at least one case, four children. It is not clear whether this is because good carers are hard to find, or because it enables economies in home modifications or case management. A significant number of adoptive parents in the UK in the 1980s have sought a second and third child with disabilities, and agencies were also not concerned about this (Macaskill, 1988). However, at least one of the Victorian foster care agencies running the Family Options program is against multiple placements in the one family, because they may jeopardize sustainable arrangements.

An argument used by the Victorian DHS against the rostered staff model is that it concentrates all the 'difficult behaviour' children in the one place, reducing the prospects for developmental gains. The image of group home as 'dumping ground' is not attractive, and may be a disingenuous attempt to dissuade parents from seeking rostered staff arrangements. But trained residential care staff may be the best bet to achieve developmental gains. A US study claimed that structured teaching strategies are essential for autistic individuals, and observed that

> ... staff members in group homes specifically designed for autistic individuals use more visual structure and adapt their communications styles more than staff in homes designed for mentally retarded clients do. (Van Bourgondien & Schopler, 1990, p 393)

For the birth parents, the foster care approach is puzzling, as they would have already tried family-based solutions – respite services, in home modifications, behavioural intervention, and exhaustive meetings to conduct assessments, and review motivations and parenting skills.

POTENTIAL FOR ATTACHMENT

At least one Victorian agency makes strong reference to improved developmental outcomes directly associated with foster care. Is this likely to be the case for all children?

One of the few longitudinal studies of foster care for persons with disabilities was described by the President of the American Association of Mental Retardation as a 'scientific analysis of foster family care... (which) should serve as a seminal work'. Over a three year period it studied 148 individuals with mental retardation and stable placement, including all the homes in the catchment area that served children. The researchers were interested in the potential for family care to influence change:

> Some may believe that moving people with severe and profound levels of retardation to less restrictive, more normalised environments will cause them to exhibit larger improvements in behaviour, or to 'blossom'. Indeed, some natural parents in the study indicated that they had placed their children outside their homes in order to optimize their development. However, the data do not support the optimistic belief that family care homes will produce dramatic departures from developmental expectations...Changes in levels of adaptive and maladaptive behaviour were not large for the people with severe and profound levels of retardation living in the family care homes that were studied. (Borthwick Duffy et al, 1992, p 163)

They concluded that, while variation in environments and caregiving did have an effect on development,

> ... foster family care placement, per se, is unlikely to result in dramatic changes in an individual's trajectory of growth. This is particularly true for people with profound levels of retardation. (Borthwick Duffy et al, 1992)

The above researchers also noted another study of 30,479 people in different residential settings, which reported relatively flat life-span developmental curves for people with profound retardation, regardless of placement type.

A UK project which has documented its experience of family based care for children with disabilities is Barnado's (Macaskill, 1988). A study in 1982, followed up in 1988, looked at children who had been ascribed very low life aspirations and were placed in adoptive families. There was much success,

> ... but there were many different situations, including ones where developmental progress slowed or regressed. Where the child demonstrated a deep-rooted inability to form any type of meaningful attachment, parents went through a period of slow and painful parental adjustments towards realistic appraisal of the future. For child-centred families it was a devastating discovery,

> and threatened the placement. (Macaskill, 1988)

Unlike the Barnado's project, for Melanie's Program (NSW), it was the first 12-18 months which was the difficult time for carers:

> Where natural parents have some years to come to terms with the impact of their child's disabilities, foster carers may deal with similar issues with a shorter time span as they come to accept that even with their best efforts goals such as mobility may not be readily achieved. (Elliot & Young, 1993)

This suggests that the decision on placement type should be informed by a better identification of which children are likely to develop attachment, and make any ensuing foster placement likely to succeed. The corollary is that placement effectiveness requires an open mind towards other arrangements.

OTHER OVERSEAS AND AUSTRALIAN LEARNINGS

Any parent who has used good and bad respite houses knows that quality and responsiveness can't be deduced from rules, structures and flowery 'philosophies'. The subtleties which mark successful human service programs from unsuccessful ones require a high degree of knowledge of the field where they are applied; and in the case of foreign 'models', a detailed awareness of the context where they have worked. What made it 'work', who decided it did, and how, should be the first questions. Statistics on successful placement, or its avoidance, need analysis.

For some time, academics and practitioners in the child welfare field have queried the relevance of US-style programs, and their local adaptations in Australia (Scott, 1993, p 5). Do we have the level of expertise to implement them? To what extent do they need refinement and differentiation? To what extent do they reflect US problems, social values, government objectives, or program potential, rather than our own? For instance, access to medical and hospital care has been claimed to be one determinant of placement of disabled children in the US, but not in Australia (Kelly et al, 1995, p 80).

In South East Michigan, specialised foster care has been very successful over a twenty year period, and two of the lead agencies, Macomb Oakland Regional Center (MORC) and its sister body, Wayne Community Living Services, claim very low breakdown rates. (Provencale, 1988; MORC, 1987) Although the MORC program has had a significant influence on Victorian policy, it may not be widely understood in Australia that very few children are now accepted into foster care in the region. In recent years, the strong emphasis on in home support on a 'whatever it takes' approach precludes many families from even 'queuing' for foster care. Not everyone in Michigan agrees that foster care or in home support are always workable, however, even people associated with the lead agencies.

Whether families in difficult situations are trying desperately to cope with in home support as their only lifeline when they would strongly prefer out of home care is not easily tested.

Whether families in difficult situations are trying desperately to cope with in home support as their only lifeline when they would strongly prefer out of home care is not easily tested. Families may tailor their expectations to the range of services offered, and gratefully accept whatever is available. Very low numbers of children in group homes are reported, but one major review notes that some children come under Federal jurisdiction, rather than State, and have been placed in congregate care settings inside and outside of Michigan (Shoultz et al, 1994, P 23). Those who want group homes for their children may leave for more sympathetic jurisdictions. An ex-MORC adviser to the Victorian DHS, Nancy Rosenau, has confirmed that in Michigan the closure of group homes was part of the MORC strategy to influence decisions:

> When there were no other choices, families were left with only foster care or NO residential placement. That made it a lot easier. (FOI, 1997)

Although long term foster care does exist in South East Michigan, the goal of adoption for children who will not be returning to the birth family's home within 6 months to 2 years has been a persistent theme. Open adoption, where the birth parents continue with an informal parenting role, is seen as developmentally desirable from the child's viewpoint. But the route to adoption is a further and inevitable step, and this extra step may not be one parents are prepared to take.

In South Australia, it has often been quoted that only about 11 children and adolescents with disabilities are in non-family based residential care (DHS, 1996). However, the statistics also require definitional scrutiny: one SA worker was aware of 6 additional children who have a lot of out of home respite but are still categorised as in 'family care' (FOI, 1997). The categorisation of children in long term respite care as being there for training, assessment purposes, emergency, or 'in transition' is notorious (H&CS, 1994, p 6). On their own admission, we know that the SA statistics on child protection and support are undeveloped (Steering Committee, 1998, p 817, p 852). Is it too querulous to suggest that this messy picture casts a shadow over the care statistics on disabled children?

Success rates of 100 per cent for the Family Options program are claimed by at least one Victorian agency. Independent scrutiny and transparency would enhance the credibility of these results. Incorporating concerns from others in the terms of reference for evaluations (such as the effectiveness of volunteer caregivers, recruitment from geographic, cultural and kinship networks, awareness of parents' cultural or religious orientation, etc.) would also help. The prospect for self-justification under the guise of evaluation is well known:

> Placement avoidance may not be a good indicator that there has been a significant improvement in family functioning. Similarly, the placement of a child may not represent failure but a positive outcome for a child. If the program is

For the future, the following issues seem important:

1. That succeeding generations of practitioners do not continue the cycle of rediscovering new solutions to the complex problems of planning care for children with attachment disorders, without being aware of the extent to which these solutions have been tried before, and of the likely associated problems. There needs to be some degree of trust and respect between generations of child welfare practitioners, as well as encouragement to each new generation to be innovative and clear-sighted in approaching current social problems.
2. Enthusiasm for policies in welfare practice which appear to be well supported by current social and psychological theories must be tempered with close observation of the realities of outcomes, and the effect on the broader social context. A relevant example is the need to be clearly aware of what is being asked of voluntary caregivers if foster care and adoption programs are expected to take on the major responsibility for long term out of home placement of children.
3. Research based on close observation is needed to further clarify the exact nature of children's behaviour disorders and the intervention strategies that are effective. Such studies should ideally encompass large samples of clients and controls, and include a longitudinal component.
4. After many years of work in this field I have reluctantly come to agree with the concept of the 'least deleterious solution' ... as opposed to the 'optimal' solution in planning for children with serious attachment disorders. To some extent the ideals of continuity and permanency of care may have to be compromised in order to give the best possible service to some children. However I also believe that it is important for children to have adults in their lives who offer continuity of concern and responsibility, and that this role can sometimes be assumed by the staff of voluntary non-government agencies who have traditionally been involved in the provision of long term care.

Sonia Russell, 'Implications for Child Welfare Practice',
Children Australia Vol 17, No 1, 1992, p. 24.

> sold to politicians and administrators as a cost cutting strategy based on placement savings, as it has so clearly been done, then the viability of the program will be seriously jeopardised if it cannot demonstrate that it can deliver these goods. (Scott, 1993, p 9)

THE POLICY PENDULUM IN VICTORIA

Practitioners have warned against the memory blackouts which sometimes afflict policy makers, where optimism, determination and supposedly new insights are regarded as making previous learnings redundant (see box, above).

Despite the recent bias towards foster care in Victoria, it was not always so. In 1989, the predecessor to the DHS did not see living in a birth family or alternative family as a viable option for children at the difficult end of the spectrum. The Permanent Care Team at the time stated that:

> Earlier in the history of the Unit as with similar units both in USA, UK and Canada the approach that 'no child is unplaceable' was taken. The approach was that all children, irrespective of age, disability and level of need could benefit and had a right to a permanent family placement. Over the 11 years experience of the unit, this philosophy has been recognised as a little unrealistic and over ambitious and that some children cannot be placed in a permanent family situation, although it also may not be possible for them to return to the care of their biological family. (CSV, 1989, p 98)

In reviewing the factors affecting 'placeability', they listed:

- the child's age: 'research clearly indicates that younger children are easier to place than children over 8 years. This is particularly so if they are physically or intellectually disabled';
- attachment potential: this is influenced by 'age, gender, and temperamental characteristics as well as the quality of relationship prior to separation';
- child's attitude and behaviour: 'A child's behaviour in a controlled setting such as congregate or residential care is often not indicative of their behaviour in a family setting, where expectations are different. Some behaviour may be difficult to manage in a family situation – for example physical, violent or aggressive behaviour or suicidal tendencies, continual absconding';
- child's physical and intellectual needs: 'Some physical or intellectual disabilities are so severe and may over tax a family. These include some children with physical problems, such as severe cerebral palsy, which require 24 hour nursing care, although the Unit has placed two such children with great success. In common with all placement agencies both in Australia and overseas, the Permanent Care Unit experiences difficulty in recruiting families for children with disabilities... (CSV, 1989)

A review of the Shared Family Care respite program in 1992 found that:

> ... the situation described from Macomb-Oakland in the USA in which many more potential caregivers were available than children with disabilities to care for, has not at this stage occurred in Victoria. (Baxter et al, 1992, p 71)

The establishment of the Family Options program in 1995 was confirmation that success was still elusive:

> Existing family placement programs in Victoria for children and young people with disabilities had been found to have difficulty in placing children and young

> people with high daily care needs on a wide scale. (Department of Human Services, 1997)

THE RIGHT TO A LIFE

The motives of those who genuflect at the altar of 'the family' should be examined carefully – not many social symbols strike a chord more powerful for those seeking public support for their ideas. In a period of privatisation and state withdrawal from direct involvement in many social and economic arenas, those affected need a clearheaded analysis, rather than accepting sentimental notions on face value. An obvious concern is that the shift towards foster care of children is the policy response to demands for increased resources, including more and better paid staff in government group homes.

Eva Cox (1987, p. 9) reminds us that 'the family is a unit, rather than being constituted of individuals, whose needs may well be in conflict, with various levels of independence and dependency.' Highlighting the role of carers (overwhelmingly women) has become a larger policy theme in recent years, although policies are more interested in propping up carers than relieving them of the care burden. A grim statistic from the Australian Institute for Health and Welfare's survey of carers is that almost a quarter of the carer population feel that their role has put a strain on the relationship with the person being cared for (Australian Institute for Health and Welfare, 1997, p 329).

In the US context, it has been pointed out that the 'right to live in the least restrictive environment' is only a half statement of the issue:

> The right to live in the least restrictive environment should apply to family members as well as to handicapped individuals. Thus (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. (Blacher, 1994, p. 217)

BUILDING FAMILY LINKS

In its focus on what it believes best for the child, there is still a limited understanding by DHS that a placement which has a negative impact on others in the family is an unsatisfactory placement. Apparently there is a substantial element in US and Australian child welfare departments who believe that parents who are unable to look after their disabled children should lose their legal rights. This is hardly amenable to pursuing a 'partnership' approach. The advocacy organisation funded by Government to represent the interests of parents and their young children is critical of the philosophical rigidity of DHS in this area (Association for Children with a Disability, 1995).

While this may be an imperfect model (like many families and foster families!), to jettison what has been achieved for the sake of another imperfect model seems madness.

For example, the DHS would not consider acceptable an arrangement where the child lives in a rostered staff home, but has a birth family who visits regularly and takes the child out, and is heavily involved in the child's educational and medical issues, behavioural plans, and management of personal development and care. This is a common situation in Victoria, and is desired by parents. Sharing these roles with another family is to weaken the links, which are reinforced by this traditional type of parental involvement. In Melbourne, examples of parents who visit their child daily at a group home or school are known to this writer but, again, this is not deemed to be sufficient involvement worthy of preserving.

Instead, stable arrangements of this sort are to be disrupted as the child is forced into a foster care model with an alternative family. In at least one case of the above type known to this writer, the Family Options agency proposed a foster family over 1½ hours drive away by car. This would certainly affect the ability to maintain visitation by the biological family. The introduction of such an intermediary may prejudice the biological family's ability to develop the existing relationship, and replace other relationships with three way negotiations with schools, therapists and the like.

The interposing of an alien family between the child and the birth family may attenuate the relationship with the birth family and jeopardise the life long advocacy and relationship continuity offered. A woman who gave her child up for adoption has commented on the impact on her psyche:

> Socially, the implied message to the mother is that she is so unworthy to be her child's parent that total strangers have a superior claim to him or her. This devaluation of her as a mother can seriously inhibit her confidence in caring for children she keeps. (*The Age*, 1998, p. 12)

While not all relinquishing parents may feel this way, the potential for destructive consequences is clear, yet never considered relevant to the placement decision, which is 'child centred'. It is interesting to note that there are some differences in permanency planning between countries, with Britain emphasising permanency away from the original family, and the US stressing family reunification (Goddard & Carew, 1993, p 229). It is not clear whether adoption is the policy goal in Victoria, despite the centrality of permanency planning! If there is such a policy, in order to provide long term security for the child, it is less relevant now, as parents are no longer expected to 'relinquish and forget.'

Building clear understandings with foster families would also seem to be important to sustainable arrangements. Failure of arrangements leading to 'foster care drift' is the reason why US permanency planning strategies suggest adoption as the inevitable next step. In the NSW Melanie's Program, one important, but perhaps forgotten, party who needed their commitment to the foster child clarified was the natural children of the foster parents: what are the expectations of them should their parents be unable to continue their foster role? Little discussion had occurred between foster carers and agency staff about the long term future of the fostered children, with the result that:

> ... a tacit expectation has been developing that Melanie's Program carers would provide if not life time care, then certainly care well into adulthood, but this expectation has not been canvassed with carers...(who) generally identified group homes rather than family care options. (Elliott &Young, 1993, p 26)

BRINGING THE CHILD HOME?

The common aim of foster care policies is to return the child to the family home, but this is often not acceptable to families. The evaluation of Melanie's Program (NSW) reported that some families:

> ... could not envisage the kind of services which might have made it possible for their child to have remained at home, and it was the view that the provision of additional resources for the family would not have avoided the need for alternate care for their children. (Elliott &Young, 1993, p. 46)

In the US, families today are not likely to place the children at birth, keeping them home for longer periods. This probably develops attachment and buffers against subsequent placement. Families who place their child outside the family home are much more likely to continue a high level of contact with their child, compared to previous generations. (Blacher & Baker, 1994, p 505) This was put down to the passage of PL 94-142, The Education for All Handicapped Children Act, which gave new service provisions and opportunities for families to be involved in their child's schooling while the child still lived at home. This higher level of involvement – visits to the residential facility, visits by the child to the home, phone calls, and involvement in the child's Individualised Habilitation Plan – continued even after the child left the home.

Blacher and Baker's (1994) study of 55 families also looked at the behavioural and emotional dimensions of family involvement and detachment over the first two years after placement of the child outside the family home, and how the families adjusted. For around half of these families, placement was permanent. Important findings were that:

- the great majority of parents reported life to be better following placement, especially in recreation, social life, and relationships with and adjustment of their other children;
- for 58 percent of families, having the child at home had led to changes in long range plans and goals, such as where they lived, what jobs the mother and/or father took, or whether they pursued further education; half the families revised these following placement.

The conclusions were that:

> ... there was not much evidence for detachment in these families ... In any event, the lack of immediate detachment is a promising finding, given the importance of continuing family involvement in the success of residential placement ... It may be that some emotional distancing already took place during the long process of deciding about placement. Still, within the first years following placement involvement was high and consistent, although patterns differed ... These are resilient families. They have lived through the difficult years of having a child with severe handicaps at home and the requisite sacrifices. They have struggled with making a professionally unpopular decision to place. And they have placed. But with it all, rather than experiencing family dissolution, parents can at the same time report an increase in well-being, the maintenance of meaningful contact, and a positive outlook. (Blacher & Baker, 1994, p. 518)

In another study, Blacher found that placement outside the home had positive effects for the majority, but with a caveat:

> ...although positive post placement adjustment is an asset for the family at home, it ultimately may be a liability for the placed child if family reunification is a goal. These families clearly are not eager for the child to return home. (Blacher, 1994, p. 235)

ROOM FOR NEW MODELS

Under Permanency Planning, a nurturing relationship between the family and child explicitly entails cohabitation, ie, living under the one roof. As currently conceptualised in the black/white world of permanency planning, more flexible or intermediate models are not entertained at all. But these alternatives do not contradict the optimism and concern for the child at the core of permanency planning.

In some cases, parents have found responsive staff and management at respite houses and developed a satisfactory outcome for their children, including program coordination and developmental gains for the child. Building on these experiences, a group home, run by rostered staff, is an attractive model for some parents and professionals. Such an option is very difficult to access with current policies. While this may be an imperfect model (like many families and foster families!), to jettison what has been achieved for the sake of another imperfect model seems madness. It is not justified by the interests of the affected parties, but by misplaced enthusiasm for a politically comfortable 'family' ideology.

In practice, arrangements made under one or another model may be hard to tell apart in terms of the important policy objectives of consistency of living location, maximising development and attachment, and long term sustainability of the arrangement. Ironically, at least one Victorian arrangement to date, favourably described as a substitute family arrangement, involves a large number of volunteer carers and shared parenting between two families at two sites.

The Center for Human Policy at Syracuse University, a leading proponent of permanency planning, provides a number of recommendations on supporting families:

> First, it is important to recognise the work that families do on a daily basis to get what they need, not only for their child with a disability but for their family. Second, we must try harder to listen to and respect the expertise that families have about their children and

> their lives. While much lip service has been given to the language of respecting parents and really listening to them, we as professionals still appear afraid to trust them. (Shoultz et al, 1994, p. 62)

To take this message seriously would mean applying the new thinking which puts the person needing care, and their significant people, at the centre of the process. These ideas favour differentiation, tailoring, and a 'micro' approach: they hold out the promise of an individual, empirical approach which does not compromise basic principles. Enhancement of a group home environment to allow high levels of family involvement must be conceded as not only desirable, but a policy imperative.

There appears to be an irrational fear in planning circles that any divergence from the two approved models – birth or substitute family – will open the floodgates to a revival of institutional living. But today's parents of young children want community living: the crimes committed against people with disabilities, and many without disabilities, in Australian institutions are well documented. 'Holding the line' against parents who believe that growth involves moving away from abstract stereotypes is, in the Australian context, gratuitous and conservative. □

REFERENCES

Ainsworth, F. 1997, 'Foster care research in the US and Australia: An update', *Children Australia*, Vol 22, No 2.

Association for Children with a Disability 1995, *Draft Response to H&CS Draft Policy Framework for Disability Services, Child Adolescent And Family Services.*

Australian Institute for Health and Welfare 1997, *Australia's Welfare 1997: Services and Assistance*, AGPS.

Baxter, C., Cummins, R.A., Volard, J. & da Costa, C. 1992, 'Shared family care: Policy implementation during the initial stage of service development', *Australian Disability Review*, 2-'92.

Blacher, J. & Baker, B.L. 1994, 'Family involvement in residential treatment of children with retardation: Is there evidence of detachment?', *J. Child Psychol. Psychiat.*, Vol 35, No 3.

Blacher, J. 1994, Placement and its consequences for families with children who have mental retardation, in J. Blacher, (ed), *When there's no place like home: Options for children living apart from their natural families*, Paul H. Brookes, Baltimore.

Borthwick Duffy, S.A., Widowman, K.F., Littlemore, T.D. & Eymack, R. 1992, *Foster family care for persons with mental retardation*, AAMR.

CSV Permanent Care Team 1989, 'Permanent care: current issues, research trends and future directions', *Child Protection Conference Proceedings*, November.

Cant, R. & Hand, M. 1994, 'Who cares for these children? An historical analysis of recent documents on provision for those with developmental disabilities', *Children Australia*, Vol 19, No 3.

Cox, E. 1987, 'Rediscovering the family: A popular political pasttime', *ASW Impact*, March.

Department of Health and Community Services (Vic.) 1994, *Respite Review.*

Department of Human Services (Vic.) 1996,'Much love for Sarah from two families', *Progress Press*, 25 June.

Department of Human Services (Vic.) 1997 *Family options policies and procedures manual: interim guidelines*, October.

Elliot, B & Young, M. 1993, *Melanie's Program Evaluation Final Report*, unpublished, November.

FOI (Vic.) documents, September 1997

Goddard, C. & Carew, R. 1993, *Responding to children: child welfare practice*, Longman Cheshire, Melbourne.

Kelly, F., Clark, J., McEntee, P. & Dench, S. 1995, *Factors contributing to the relinquishment of children with intellectual disability*, IDSC, South Australia.

Letter to *The Age*, 21/2/98 p 12

Llewellyn, G., Dunn, P., Forte, M., Turnbull, L. & Grace, R. 1996, *Families with young children with disabilities and high support needs*, University of Sydney Family Support and Services Project.

Macaskill, C. 1988, 'It's a bonus': families' experiences of adopting children with disabilities', *Adoption and Fostering*, Vol 12, No 2.

Mason, J. 1996, 'Privatisation and substitute care', *Children Australia*, Vol 21, No 1.

MORC 1987, *Recruitment of foster homes: an instructional manual of foster home recruitment techniques*, Macomb-Oakland Regional Center.

National Institutes of Health 1990, 'Consensus development conference statement, treatment of destructive behaviours in persons with developmental disabilities', *Journal of Autism and Developmental Disorders*, Vol 20, No 3.

Provencale, G. 1988, *Characteristics of a successful community living program and support service*, Yungaburra Foundation, Melbourne.

Russell, S. 1992, 'Implications for child welfare practice,' *Children Australia*, Vol 17, No 1.

Schopler, E. & Van Bourgondien, M.E. 1990, Special Issue on Residential Services, *Journal of Autism and Developmental Disorders*, Vol 20, No 3.

Scott, D. 1993 'Issues in transplanting programs from the US, *Children Australia*, Vol 18, No 2.

Shoultz, B., O'Connor, S., Hulgin, K. & Newman, P. 1994, *Permanency planning in Michigan: From philosophy to reality*, Center On Human Policy, Syracuse University, New York.

Steering Commitee for the Review of Commonwealth State Service Provision, 1998, *Report On Government Services, Vol.2*, AGPS.

Van Bourgondien, M. & Schopler, E. 1990, Critical issues in the residential care of people with autism, *Journal of Autism and Developmental Disorders*, Vol 20, No 3.

Whittaker, J.K. & Pfeiffer, S. 1994, 'Research priorities for residential group care', *Child Welfare*, Vol 73, No 5, Sept-Oct.