Working together works well

A longitudinal evaluation of a family-based placement program for children with a disability and very high support needs

Julie Hind and Judith Woodland

This paper is based on a three-year longitudinal evaluation of a family-based placement and support program for children with disabilities and high support needs. Particular lessons emerged about the importance of partnerships: between caseworker and alternative family; the alternative family and the birth family; and the caseworker and the birth family.

The evaluation used case studies, following ten children through the life of the study. A qualitative approach drew on people's experiences to understand individual perspectives and to identify patterns and themes to gain insight into the factors contributing to success.

The study was informed by international literature, including: Maluccio et al (1983, 1986) and Smith (1995) in relation to permanency planning; Thoburn (1986, 1990, 1994) and Wedge (1986) in relation to hard-to-place children; and Argent and Kerrane (1997) who demonstrate that continuing contact between birth and alternative families can work well with support from workers.

This article focuses on one part of the evaluation – the development of relationships. The relationship between the caseworker and the alternative family is a key to the success of the placement. In the best examples of good practice, the relationship is one of partnership, with both partners having the interests of the child as their central focus.

The partnership is not evident in dealing with birth families. We note the strongest relationships are where birth families have an ongoing role in caring for their child. In some cases, the alternative family takes on a role of supporting the birth family's ongoing involvement with their child.
The paper explores the different relationships and points to further possible areas of future research.

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What works to sustain the long-term well being of children who have disabilities and very high support needs? Our 2000 evaluation of the Family Options Program in, commissioned by the Department of Human Services, Victoria, shows that significant outcomes are achieved when families, be they birth families or alternative families, are empowered and enabled in their caring role. The application of individualised supports that come as part of a flexible care package and as a result of a family-centred practice model, in which families are central to the decision-making, are key tools. When the relationships between the key people develop into partnerships, families report feeling more empowered and supported and the outcomes for the children are strengthened.

A WORD ABOUT TERMINOLOGY

We use a number of terms throughout this paper when referring to families. 'Birth family' is self-evident. 'Alternative family' is the name chosen by families who have taken on the care of a child through the Family Options Program. We use 'primary carer family' to refer to either of these when they take the lead role in caring for the child. The term 'foster family' only occurs in discussion of some literature.

THE EVALUATION

Between 1996 and 2000, Evolving Ways undertook a longitudinal qualitative evaluation to inform the implementation of the Family Options Program and to assess its effectiveness. At the time, the Family Options Program was a developing and innovative family-based placement program for children with disabilities and very high support needs who could no longer live with their own families. Children supported by the program have an intellectual, physical or sensory disability, typically a combination of these, and very high support needs due to their high level of physical dependence and/or extremely challenging behaviours.

The Family Options Program's philosophy – that family-based care is the most desirable long-term living arrangement for children with a disability – is based on the underlying principles of permanency planning from the work of Maluccio and others (Maluccio & Fein, 1983; Maluccio, Fein & Olmstead, 1986). The Program has three

components: ongoing case management, caregiver reimbursements, and a flexible financial package consisting of placement establishment funding and recurrent discretionary funds.

The Program was established within the context of an extremely limited service system for children with high support needs and their families. Permanent placement of children into residential care had all but ceased and the State was redeveloping the last significantly sized, facility-based, accommodation service for children. Families had few ongoing supports to meet their diverse needs. Respite was the major service system response and many children were subsequently residing in respite facilities in an almost permanent way. This led to a reduction in the availability of respite and, as a result, had dire consequences for other families in need.

Funding was initially provided for thirty Family Options places and priority was given to children residing in respite facilities, full-time or part-time, and those who were to re-locate from the congregate care facility.

Our evaluation was planned to commence soon after initial implementation of the Program. It comprised three phases, each of approximately twelve months, over a 3½ year period. Our evaluation framework acknowledged the interdependence of the various program components. We considered the individual and collective impact of four components:

- Processes: the way in which people go about their respective roles;
- Relationships: the ways in which people work together to support placement;
- Characteristics: of the children, their families, the alternative families, the workers, the agencies and the regions; and
- Resources: what, when and how resources are used.

This paper looks at only one of these components – relationships – and then only at the relationships the Family Options worker developed with the primary carer (most often an alternative family) and the child's own family, where they were not the primary carer. A final report to the Department of Human Services details all of our findings (Woodland & Hind, 2001).

EVALUATION APPROACH

A major strategy of our evaluation comprised case studies, following ten children, a third of the initial intake, through the life of the evaluation. As the evaluation was to inform a developing program, a representative sample was selected purposively with the service provi[illegible] ensuring: a range of ages, both sexes, rural and urban, a range of pre-program living situations, varying levels and intensity of ongoing parental involvement, and a range of pathways to the program. The ten children were aged between 6 and 14 years at the start of the study. All had multiple, severe disabilities, with characteristics that traditionally attracted a perception of being hard to place.

Our qualitative approach drew on the experiences of the families, alternative families, Family Options workers and, where possible, the child. We needed to understand individual perspectives and to identify patterns and themes to gain insight into the factors contributing to success. We used in-depth interviews, employing an open-ended questioning technique within a broad thematic framework.

Direct language of the respondents was used for purposes of analysis. Data was analysed according to the components of the evaluation framework and according to emerging themes. Interviews were conducted twice during the first and second phases and once during the third phase.

To assist in the further development of the program, it was agreed with the commissioning agent and the service providers to include a further eight children and young people during the second phase of the evaluation. These additional children were included in the evaluation to capture particular practice issues that had arisen during program implementation and to include agencies and regions that had taken up the program in the second intake. Interviews were conducted with key informants in this group once, and in some instances, twice.

Data providing worker assessments of outcomes for all of the children and young people was collected in the third phase.

Our evaluation was informed by a literature review conducted in the first phase and updated in the third. Other aspects of the methodology included interviews with departmental staff and workshops that enabled feedback and reflection by key groups, particularly workers, alternative families and birth families.

WHAT OUTCOMES WERE ACHIEVED?

Our study used three main measures of success for the children and young people, based on participants' desired outcomes. These were:

- stable placement (Thoburn, 1986;1990; Kermode, 1990; Reich & Lewis, 1986);
- nurturing relationships (Thoburn, 1990; Wolkind & Kozaruk , 1986; Triseliotis, 1983); and
- quality of life (Thoburn, 1986).

With these as our measures, our study found that positive outcomes for the children and young people were significant.

By the end of the evaluation, eight of the ten children in the longitudinal case studies had been living with the same alternative families for up to four years. One had

experienced a disrupted placement and was now in a second, stable situation. The tenth, a young person nearing 18 years of age at the time, left the program after two years with an alternative family because of changed life circumstances in that family.

The nine children who remained with alternative families were in nurturing relationships, as defined using Thoburn's (1990) indicators of permanence – security, belonging, family life, being loved and loving. We found attachments had been formed and long-term commitment was evident.

We believe the family-centred practice model, a central feature of the Family Options Program, helps people to build strong, positive relationships.

Quality of life was judged using determinants identified by key participants – family life skills, general well being and happiness, family and community interaction, health status, having choices and control, and a good physical environment. Significant gains were found in all of these areas and were reported by key people as being greater than would be expected just through maturation.

Children made gains in communication, daily living skills and social interaction. Where behaviour was an issue, children made significant gains in developing more appropriate behaviours. All children made gains in general health and well being, as evidenced by reduced hospitalisation, fewer respiratory tract infections, gaining weight and informants reporting increased happiness. All children were participating in a wide and diverse range of social and community activities with their alternative families and were part of the alternative families' personal networks. Many had more choice and control in their lives, making choices about everyday living situations – what to eat, what to wear, how to spend leisure time – in a way that had not been possible previously.

THE ROLE OF RELATIONSHIPS IN CONTRIBUTING TO THESE OUTCOMES

A number of factors contributed to these outcomes. Our evaluation suggests one factor to be the relationship between the primary carer and the worker. We found that in each of the successful placements, the primary carer(s) and the Family Options worker had developed a strong bond of mutual trust and respect.

> I trust the worker and team to do the best for Jane and she trusts me to look after Jane [alternative family].

The workers had a strong belief in the primary carers' ability to successfully care for the child in a nurturing environment. They valued the role of the primary carer and provided regular feedback to them about the value of their effort. The worker was accessible to the primary carer yet gave them the space to get on with raising the child.

> We don't have to keep in touch with her too often ... We agree what will be done and then we do it [alternative family].

The primary carer trusted the worker to advocate for them and the child, to be available when needed and to help put appropriate supports in place. The primary carers reported feeling empowered, and they appreciated being able to 'get on and do it'.

In all of the case studies, trust and respect were also reflected in the way the financial resources were accessed and used. Where a strong, positive relationship had developed, the processes relating to financial resources were transparent, simple and quick, and provided the primary carers with a negotiated level of autonomy. Where a strong, positive relationship had not developed, conflict arose in relation to financial matters.

The strong bond with the Family Options worker enabled the primary carers to deal with extremely difficult situations. Our finding was similar to that of Redding, Fried and Britner (2000) who found that none of the characteristics of the child or the foster family is nearly as important as the rapport between the foster family and the caseworker. They found that successful placements could be achieved even for 'more difficult children' (p. 437) where there was a strong relationship between foster family and caseworker.

However, we did not find evidence of strong, positive relationships between the worker and the alternative families in the two cases that experienced placement disruption, even though the placements had lasted for between one and two years. In both instances the needs of the alternative family were not readily acknowledged, their requests for support were often denied, their motives were often questioned, and decision-making processes were controlled by the agency. These two alternative families regularly found themselves in conflict with their worker and the agency. They believed they were not valued, even where they had helped the young person in their care to achieve significant improvements in social, behavioural and other life skills.

WHAT HELPS BUILD STRONG, POSITIVE RELATIONSHIPS?

We believe the family-centred practice model, a central feature of the Family Options Program, helps people to build strong, positive relationships. Dunst, Trivette and Deal (1988) defined family-centred models as practices that are client-driven, in which families' needs and desires determine all aspects of service delivery and resource provision. Professionals are seen as the agents, intervening in ways that

promote family decision-making, capabilities and competencies. Resources and supports are provided to strengthen a family's capacity to build its own network of resources.

A family-centred practice is empowering. Critically, as described in Dunst et al (1988), the alternative families in our evaluation felt capable. They were able to attribute many of the changes in the child's situation to their own actions, and not only to the support and actions of the Family Options worker.

Of note, we did not find evidence of this approach in the two situations that experienced placement disruption. In both instances, the relationship between the worker and the alternative family was much more paternalistic. It was a more traditional approach in which the caseworker was the 'expert' professional facilitating activities and interventions on behalf of the client.

These particular workers did not use a strengths-approach, inherent in family-centred practice. Their approach was more akin to a problem-solving one (Comptom & Galaway, 1984, cited in Early & GlenMaye, 2000). The workers' goal setting and interventions were bounded by agency structures and they described situations in terms of problems to solve, rather than opportunities to see what might work.

While the absence of a family-centred practice was not the principal cause of these two disruptions, it made for a more troubled caring situation because the needs of the respective families were not paramount in the decision-making process. This appeared to affect the alternative families' capacities to continue when their personal life situations altered.

DEVELOPING PARTNERSHIPS

We found that in three or four instances, a stronger relationship developed between the Family Options worker and the alternative family. We describe this as a partnership.

The literature is relatively silent on a useful definition of *partnership*. Thoburn (1999) assigns the following principles to a partnership:

- respect for one another
- rights to information
- accountability
- competence and value accorded to individual input.

> In short, each partner is seen as having something to contribute, power is shared, decisions are made jointly, roles are ... respected ... (p.55).

Where a partnership had developed, we found it was based on a joint approach between the Family Options worker and alternative family. They worked together in defining problems, goals, strategies, and success (Early & GlenMaye, 2000). Together they determined what was required and how to achieve it. Chosen activities and interventions were based on the alternative family's vision and hopes for the child and themselves. There was an optimistic future-oriented flavour to the planning and decision-making rather than a focus on simply solving problems.

A creative approach to achieving what was required was a characteristic, with the Family Options worker and alternative family collaboratively exploring a range of formal and informal resources. Workers did not create dependency. Their input was discussed and negotiated with the alternative family and clear parameters were established.

> I see coordination and organisation as my role [alternative family].

Like Early and GlenMaye (2000), our evaluation showed that partnerships meant Family Options workers did not have the total responsibility for making things work. They and the alternative family shared responsibility for achieving successful outcomes for the child. Together, they accessed resources, learned skills, and practised behaviours that they collaboratively decided would improve the family's life (Early & GlenMaye, 2000).

Roles of the Family Options worker and the alternative family were mutually supportive and were complementary. The partnership recognised alternative families as experts and critical contributors to goal setting, planning, decision-making and achieving outcomes for the child. Information was readily shared and each partner had a strong sense of being accountable to the other.

> I organised a meeting with the respite carers. [The worker] came but she didn't need to say anything. I made the arrangements [alternative family].

The shift from strong relationship to partnership is a subtle one, as many of the characteristics remain the same.

In trying to explain the progression, we found some resonance with the discussion in relation to a shift in power put forward by Turnbull, Turbiville and Turnbull (2000). In describing how the delivery of early childhood intervention services have evolved over time, they refer to a shift in power from 'power over' to 'power-with' to 'power-through'. In the latter stages, power within a relationship is transformed from controlling events and resources, to building capacity of all participants.

WHAT HELPS BUILD PARTNERSHIP RELATIONSHIPS?

We saw the family-centred practice model as a significant tool in developing a partnership. There appeared to be a natural progression in those situations where alternative families were feeling in control of their situation and were able to attribute changes to their actions, and where Family Options workers clearly recognised that their own input, while important, was only part of the whole.

Where a partnership developed, it did so over time. This accords with Thoburn (1999) who noted that it takes time to establish working partnerships. The Family Options workers were prepared to spend the time further developing the relationship, and, importantly, their agencies supported this. The relationships were not left to simply 'emerge' (Berridge, 1999, p.96) but were seen as a priority in themselves.

Where a partnership had developed, we observed the Family Options workers had, throughout the period, worked in ways that suggested a commitment to building more equal relationships with the alternative families. They were inclusive of the alternative family at each stage of the process. From the outset they were able to identify strengths in the alternative family and to value these. They tolerated differences of opinion. At all stages of the process, from initial meetings, through recruitment to post placement, these workers appeared to practise the partnership principles (Thoburn, 1999).

The partnership recognised alternative families as experts and critical contributors to goal setting, planning, decision-making and achieving outcomes for the child.

The caseworkers seemed willing, and skilled, to practise and develop a partnership and they were obviously engaged with alternative families who also seemed willing to participate in a partnership.

Willingness and skill can help explain why we found some partnerships and not others. So, too, can the notion of a continuum of family involvement (Thoburn, Lewis & Shemmings, 1995), in which full partners are found at one end of the continuum, families who are not involved at all at the other, with those participating to a considerable extent occurring in the middle. While Thoburn relates the model to birth families, it has application in our study because of the family responsibility accepted by alternative families. In Family Options, the nature of the commitment of alternative families and their caring role means that none are at the 'not involved' end. A few are at the partnership end.

An important observation in our study was that workers who were practising the principles and developing partnerships seemed not to be doing it as a conscious practice but rather innately. While they had a formal family-centred practice framework, and reflected upon this in an ongoing way, none appeared to have a formal partnership practice framework. As a result, none of the workers had, within their training or supervision, a strong analytical and conceptual framework for understanding and working with families in a partnership. We believe that this limited the development of some potential partnerships.

Two examples help to illustrate this. The first was in relation to alternative families being strong advocates for the children. We found they have high expectations and are persistent in achieving what they believe is needed. This meant, from time to time, that they were very demanding. Where the caseworker did not have a framework for understanding and working with families in a partnership, the demands of the alternative families placed pressure on the relationship. The caseworkers in question mistook such demands as unreasonable, and the alternative family as troublesome.

The second example was in direct contrast. A caseworker acquiesced to very strong demands of an alternative family for particular respite arrangements that helped to further displace the birth family from the child's life. This caseworker mistook such demands as reasonable and overlooked the importance of working together in the best interests of the child.

The absence of such a framework could help explain why so few caseworkers developed partnerships, at least within the period of our evaluation. We suggest workers need an analytical and conceptual framework for understanding and working with families in a partnership. This framework should be included in training and supervision of workers.

WHAT WERE THE RELATIONSHIPS WITH BIRTH FAMILIES CARING FOR THEIR OWN CHILD?

In the wider study cohort, a small number of birth families were the primary carers, either full-time or part-time. Whilst there were strong relationships evident, it is our belief that none had developed into a partnership. Even where a birth family did not appear averse to participating in a partnership and the relevant caseworker seemed to have the willingness and skills, as evidenced with alternative families, the relationship did not develop to this degree.

These findings suggest to us that something else is in play and we posit that it might relate to the notion of viewing families through different lenses – one lens that views the alternative family with awe for the task they are willing and able to undertake, and another lens that views the birth family as needing assistance.

Valuable information could be gained from additional research focused on these families and their caseworkers, and others who are supported through the program to care for their children, to assess whether partnerships have developed.

WHAT WERE THE RELATIONSHIPS WITH OTHER BIRTH FAMILIES?

We feel that the opportunities to reflect on relationships with families has provided some valuable pointers to further research on supporting birth families of children with disabilities and high support needs.

In our study, the quality of relationships was a strong indicator of continuing birth family involvement with their child. We observed that where caseworkers and alternative families were inclusive of the child's own family in the decision-making processes and in the child's day-to-day life, birth families were more likely to remain involved. Where they showed signs of respecting the level and type of interaction families chose to have with their children, birth families reported more positive feelings about the placement.

... where caseworkers and alternative families were inclusive of the child's own family in the decision-making processes and in the child's day-to-day life, birth families were more likely to remain involved.

Ongoing support to the child's own family is a feature of the Family Options program, reflecting the longstanding recognition of the importance of maintaining family ties between parents and their children who are in alternative care (Maluccio, 1981). Contact by families provides important continuity and stability (Berridge, 1999) and helps build a sense of identity (Thoburn, 1990). This sense of identity has been found to be true for all children, whether or not they have a disability (Phillips, 1998).

We found caseworkers' support to birth families who were no longer caring for their children varied from irregular telephone contact to use of discretionary funding to maintain the family's involvement. In the early stages of the program, direct support to birth families appeared less common. Over time, more supports were being provided to birth families to stay involved with their child.

The field has long recognised the worth of family-centred practice in helping to maintain family involvement (Maluccio, 1981). As previously stated, our study suggests the family-centred practice in this program helped to build strong, positive relationships with alternative families. With birth families, we found a family-centred approach where a birth family was also primary carer, either full-time or part-time. On the whole, the practice with birth families was paternalistic, similar to that with the alternative families in the two placement disruptions. Consequently, the quality of the relationship between the Family Options worker and the birth family was not as strong as that between caseworker and alternative family. They received very little casework attention compared to the alternative households (Berridge, 1999).

In considering the relationship between caseworker and birth family we pose the following question: If we have long known the importance of a family-centred model and its link with helping to maintain ongoing family ties, why were caseworkers not practising this with birth families?

Whilst we do not have definitive answers to this question, we do propose four inter-related possibilities.

Firstly, several caseworkers in our study found a lack of time and energy worked against supporting both families in a family-centred model. This could suggest that the model of a single caseworker supporting all three central parties – child, alternative family and birth family – might not be the most conducive to more fully engaging the birth family. The long-term nature of the caring role of the alternative family in this program means the focus is on making this arrangement work well. There is not usually a goal of returning the child to the care of the birth family. In this way, it is more like permanent care than foster care.

Secondly, when birth families do not have an ongoing primary care role, caseworkers appear to have trouble helping them find a meaningful role in the child's life (Masson & Harrison, 1999; Berridge, 1999). Some caseworkers had difficulty in taking a long-term view of family ties and the role the family can play in the life of the child (Masson & Harrison, 1999). This raises the question of how committed caseworkers are to preserving family ties. For some, the potential outcomes of preserving the ties did not appear to warrant the efforts required. How well grounded are caseworkers in the relevant theory and would greater attention through training and supervision alter their perceptions?

Thirdly, most caseworkers in our study placed their focus on the alternative family. They appeared to practise a narrow, family-centred model that concentrated on the child's 'nuclear' family, that is the primary carer family. Their practice did not appear inclusive of the child's 'extended' family, in these cases the birth family. Might an extended framework that is inclusive of both families make a difference to practice?

Lastly, birth families participating in the case studies reported years of stress and difficult experiences that brought them to seek out-of-home placement for their child. Some reported that their experiences with the service system compounded their situation rather than alleviated it. The cumulative effect of their experiences may well have limited

their willingness or capacity to engage in strong relationships within the Family Options program.

BROADER IMPLICATIONS

While the Family Options program was initially established to support children in alternative family placement, agencies quickly moved to provide support to a few birth families where it was possible to avoid alternative placement through the judicial use of available resources. By the end of our study, increasing numbers of children were being supported through the program to remain living with their own family, either full-time or part-time.

At a policy level, there is now a willingness to find ways to provide sufficient support to families of children with disabilities to prevent the development of crises of such magnitude that they feel an alternative care arrangement is the only option for them. Lessons from the Family Options program indicate that the provision of material resources needs to be complemented by the development of partnerships with birth families.

This will require a change of practice that is supported by an appropriate analytical and conceptual framework and relevant training and supervision.

SUMMARY

In summary, then, our study suggests that strong, positive relationships aid in achieving child outcomes. The literature indicates partnerships as the benchmark. It seems there are six key factors to successfully developing partnerships:

- family-centred practice;
- adherence to the defining principles of partnerships at all stages of the process;
- a willing and skilled caseworker;
- adoption of a formal partnership practice framework;
- agency support for the caseworker through training, supervision and agency procedures; and
- a willing family.

In this evaluation, there is evidence of this working well with families where all, or most, of the above factors are in place. □

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