Record

120

File Number

10093

Author: Baxter, Christine

Title: Caring for Children: *Sharing the Care of Children with Intellectual Disabilities: A Parent - Care giver Partnership*

Original source: Interaction Volume 5 Number 6 1991/1992

Resource type: Written

Publisher Info: NCID

Publication Date: 1/1/1992

Abstract

This article was written by Christine Baxter of the Deakin University Department of Intellectual Disabilities which conducted an evaluation of the Shared Family Care program which operates in Victoria. This program operates respite care, short and long term care for children with disabilities and their families or primary care givers. Referred families are matched with care givers thus extending the parent's network of supports and allows parents and care givers to work together. **Keyword: Respite. Searchword: Accommodation**

Sharing the Care of Children with Intellectual Disabilities: A Parent-Caregiver Partnership?

Christine Baxter
Department of Intellectual Disabilities
Deakin University
Victoria

Caring for a child with a disability can be stressful for families faced with the day-to-day care of their child. These problems are often greater in countries such as Australia where care of children has traditionally been viewed as the responsibility of parents alone. Parents have been expected to cope by themselves without the extended family and neighbourhood network which is so crucial to the care of children in some other societies. So what happens when the care of a child with a disability is shared by other families in the community? How can such an arrangement work? What are the successful and unsuccessful outcomes of the arrangement? How do parents and caregivers view the experience?

With questions such as these in mind, we conducted an evaluation of Shared Family Care (SFC) which operates in Victoria. This program provides respite care, short-term and long-term care to children with intellectual disabilities and their families or primary caregivers. The evaluation was designed to look at the progress made during the initial stage of program development. We conducted a content analysis of government documents and interviewed parents, caregivers, and the service providers. Some of the major findings of the evaluation conducted so far have been summarised under the headings that follow.

Developing the Idea of SFC

The policy documents of SFC indicated that several notions have been considered important in the development of the SFC initiative. In the first place, SFC was considered to be preferable to a community residential unit or institutional care because it more clearly provides a nurturing and stimulating environment which meets the child's dependency, modelling and social needs.

SFC was conceived as a flexible arrangement in which the extent of the care provided would vary according to the needs of the child and the family. In the case of 'respite care', this was viewed as being of short-term duration and planned to occur regularly or occasionally throughout the year. In the case of longer term care, the child might live with the caregiving family for up to two years. The special needs adoption program was set up for children in need of persistent long term care. Through these means SFC was conceived as making available to children with intellectual disabilities, the same out-of-home options as non-disabled children and providing families with a choice about the kind of service which best meets their requirements.

How Does SFC Work?

The program is funded through the Intellectual Disability Services budget of Community Services Victoria, but is administered by the Placement Support Branch of CSV. There are two notable features of the program as it operates in Victoria. In the first place, the program is generic and is run within foster care agencies. Secondly, the

caregivers are unpaid but receive an allowance to cover expenses.

A disability resource worker (experienced in the disability area) was employed in each of the six agencies funded to run the program. Their job was to provide support and resources to the agency staff in all aspects of their work with children who have an intellectual disability and to ensure an adequate focus on disability related matters. These resources included appropriate methods of publicity, recruitment, and training of caregivers and the provision of supports for the successful operation of the program.

Access to SFC

Referrals to the program had come mainly from Disability Services. However, some parents had referred themselves, which suggests that SFC is becoming known in the community of parents. Reasons for referrals to SFC were most commonly a need for respite care in order to give parents a break, stress related to the child's disability. In addition, some children had been moved out of residential facilities. Parental hospitalisation accounted for a few referrals.

During the first year of operation children had been referred into each of the official categories of SFC. Most had been in the category of 'planned recurrent respite care' (46.2%; N=66), 'emergency care' (23.1%; N=33), or 'long term care' (18.9%; N=27). However, 'pre-adoptive placements' and 'extended planned family placements' had also been made. The range of intellectual disability in the children referred was from mild to severe and many of the children had multiple disabilities.

In all of the agencies, the situation of the family and whether the family would benefit from SFC was the most important consideration for entry into the program.

In processing the applications for SFC, providing the eligibility criteria were met, the referred family was either matched with a caregiver, placed on a waiting list or referred to another agency. Generally, the agencies attempted to match the needs of the child and those of the caregiving family. This matching process involved taking account of the routines and lifestyle of the caregiving family as well as personality factors in the child and the caregiver. Caregiver preferences were considered important and caregiver capacity to cope with the child's disability within the limitations imposed by their home environment, was also assessed.

Shared Family Care placements were reviewed by the agencies through regular visits and the success of the placement was reviewed following each stay.

Recruitment, Assessment & Training of Caregivers

Caregivers had been recruited by a variety of publicity strategies including a brochure which focused on questions such as: "What is SFC?"; "Why do families use this service?", "How can I help?", and "Who can be an SFC caregiver?". A list of all agencies offering SFC was included in the brochures.

During the first year of evaluation, 33 potential caregivers were assessed by the Foster Care Agencies as being suitable to take SFC placements. All of the agencies had well-developed selection procedures and guidelines to follow when selecting caregivers. During the assessment process, caregivers indicated their preference for SFC and whether they were interested in respite care, emergency care, or long term care of a child.

Caregivers also indicated a preference regarding the age or sex of the child they wished to care for. In order to make an assessment of their suitability for SFC, up to three home visits were made to the caregiver's home. A recommendation from the worker was then presented to the Accreditation Committee.

SFC caregivers generally received the same agency-based training as that given to other foster caregivers. Training was sometimes conducted in groups and sometimes individually. Disability resource workers, general foster care workers, therapists, physicians and behaviour management specialists had participated in the training sessions. In all but one of the agencies, current caregivers had been involved in the training sessions. Two agencies had included parents in their training sessions.

All of the caregivers interviewed expressed satisfaction with the training they had received.

Characteristics of Caregivers

Many of the recruited caregivers had already had some contact with disability through a family member, knowing someone with a disability, or having previously worked in the disability area. Caregivers were mostly married with children of their own but included a single parent and couples without children. They ranged in age from mid-20s to early fifties but most were in the range 30 - 45 years.

Reasons for interest in SFC

Most of the caregivers had been recruited from the general caregiver pool. Reasons for their interest in the program included: wanting to extend their experience in fostering into the special needs area; having an interest in disability; having a desire to assist families who needed some support; and responding to the greater challenge required by children who have disabilities. Caregivers also referred to items in newsletters and foster caregiver information sessions as the reason for their interest.

Services Provided to Caregivers

During the period of the evaluation most of the agencies had referred at least one caregiver to respite care services. These included day services such as Specific Home Help and residential care. Family support services had also been used. These included: early intervention; a toy library; domiciliary care; physiotherapy; and speech therapy. A range of disability services had also been used by caregivers.

Arrangements regarding duration of time spent by the child with caregivers were made via agency staff. The responsibility for the day-to-day routines and care of the child was left to the caregiver. However, in four agencies the caregivers had access to an emergency number or paging system which they could use to contact agency staff.

During each month of the evaluation period at least five caregivers in each of the six agencies were temporarily unavailable. Reasons included family crises such as hospitalisation of either the caregiver or a member of the caregiver family. Some caregivers took breaks through the year, some travelled overseas, and one had a baby.

Parents & Caregivers

Introductory visits between parents and caregivers were arranged by agency staff. Sometimes this meeting took place in the agency and sometimes in the home of the caregiver or parents. Caregivers indicated that their relationship with parents was relaxed

and open, and that they rarely needed to make contact with parents during the placement. Nevertheless, all of these caregivers felt able to contact parents should they have a need to do so.

Caregivers' View of SFC

The caregivers viewed SFC as a positive experience for families; enabling families to take a break from ongoing care of their child. Both caregivers and parents shared the view that caring for a child with a disability was more demanding than caring for a non-disabled child. They mentioned greater responsibility, greater effort, and more physical demands because of the child's dependence. Two caregivers commented about such negative impacts as reduction in freedom, being housebound, and exhausted. Nevertheless, all of the caregivers spoke of positive aspects of the experience. Comments were made such as:

- We are still glad we took her;

- I have greater social contacts now through the agency;

- It is good to know we are taking the pressure off the family for a time.

Parents' Concerns about SFC

The seven parents interviewed had very few concerns about the SFC program. Rather, they expressed gratitude that another family could help to care for their disabled child. The only concern expressed was in relation to long-term care and then only about the permanency of the placement and the future. For example, one parent said:

- I wonder about the commitment of the caregiver because looking after my child will be a lifelong thing.

Another parent said:

- I would hate him to go from family to family. I hope the family will be able to cope in the long term.

Impact of SFC on the Child

Parents believed that SFC had been a positive experience for their child. Comments such as the following were made:

- He has been exposed to a new environment and new experiences;

- He is a lot happier, he gets a lot of attention and stimulation from the caregivers because they have more time to spend;

- He has developed intellectually and seems happier. The caregivers are able to access services we couldn't.

Parent Satisfaction with SFC

The interviews with parents suggested that they were satisfied with the support they had received from the agencies. The parents using respite care expressed a need for flexibility in meeting their respite care needs and some felt in need of more respite care than was currently being provided. The parents interviewed felt that the agency was accessible to them should they need to talk to a worker about any concerns.

Parents made only positive comments about their experience with SFC. As one parent said:

- My life has improved. There is less stress. The family was falling apart. It is much easier emotionally having someone to help.

Other comments from parents were as follows:

- It has helped me to bring up my other children and to give more time to my other children. It has also enabled me to continue with my work.

- I feel we have a new member of the family in my caregiver and we need to be close. It offers a family environment to my child so that he can grow and develop and learn.

Conclusion

Services to children with intellectual disabilities and their families have not always achieved the objectives to which they have aspired [Baxter 1987; 1989]. However, this evaluation indicated that Shared Family Care has already achieved objectives in keeping with those that led to its establishment. This out-of-home family care option, which was previously only available to non-disabled children, can now be used by children with intellectual disabilities and their families. Families in need of an out-of-home placement for their child now have a choice about whether family care or a residential placement best meets their requirements. Moreover, children with a range of intellectual disabilities and multiple physical or sensory disabilities and their families have gained access to the program. [Baxter, da Costa & Volard 1991]

SFC quite clearly extends the parents' network of support within the community and in this sense can be seen to be empowering families [Dunst, Trivette & Deal 1988]. Parents and caregivers working together in mutual understanding of the pressures attached to caring for a child with a disability, have shown what is possible in community care when this care is shared by families within the community.

Undoubtedly, the most important factor when evaluating a new service is the question of whether service users are satisfied with the service. In the case of SFC, parents and caregivers have each indicated their satisfaction with the program and already there is a waiting list of parents who wish to use SFC as soon as caregivers can be recruited.

References

- Baxter, C. Volard, J. da Costa, C. (1991)
  Shared Family Care in Victoria: An Evaluation of the Initial Stage of Program Development. Summative Report to Community Services Victoria, Disability Services. Victoria College & Phillip Institute of Technology: Disability Program Evaluation Unit.

- Baxter, C. (1987)
  Professional Services as Support: Perceptions of Parents. Australia and New Zealand Journal of Developmental Disabilities, 13, 243-253.

- Baxter, C. (1989)
  Parental Access to Assistance from Services: Social Status and Age Related Differences. Australia and New Zealand Journal of Developmental Disabilities, 15, 15-25.

- Dunst, C. Trivette, C. & Deal, A. (1988)
  Enabling and Empowering Families: Principles and Guidance for Practice.
  Cambridge MA: Brookline Books.