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Abstract

This paper describes the workings of a parent support group in Victoria for children who have disabilities in a rural area. It summarises the areas the group has nominated to be of great importance and notes some of its achievements. **Keyword: Families**

THE ROLE OF PARENT SUPPORT GROUPS IN RURAL AREAS: A CASE STUDY

Benalla Support Group for Children With Special Needs

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This paper will describe the working of a parent support group for children with special needs in a rural area; the functions of that group and our argument for the very significant role of a parent support group with a paid co-ordinator.

The Benalla Support Group consists of twenty-two families with twenty-three children with special needs. About half of the children are pre-school age; the remainder attend various schools. The disabilities include rare syndromes, Down Syndrome, cerebral palsy and developmental delay. The group has weekly meetings, educational programs, social activities and a varied educative role in the local community.

The group arose from four mothers meeting each other at a physiotherapy clinic. These mothers decided to seek funding through Commonwealth Schools Commission Educational Programs for Severely Handicapped Children and were granted \$3,500 to appoint a Co-ordinator - Parent Support Worker.

The group then decided on their aims which are:-

- a) Offer support and education for families with children with a disability to enable them to participate effectively in their community.
- b) Increase parent awareness by development of parent education programs.
- c) Promote and advance the rights of the child with a disability in the eyes of the State and Federal Governments and the local community.
- d) Ensure the existence of adequate services and facilities for children with disabilities and their families.
- e) Facilitate more efficient service provision through parental planning, participation and management.
- f) To promote and encourage a spirit of co-operation with personnel and organisations with children with disabilities and to encourage co-operation with other organisations.

The group then proceeded to appoint a Co-ordinator and the duties of this role are:-

- a) To increase parent awareness and knowledge of services that are available and to act as a consumer advocate particularly where choices are not available or access is difficult.
- b) To develop a view of local needs and priorities of families with children who have a disability or delay so as to inform government of service needs or facilitate the development of such services.
- c) To plan for and facilitate the establishment and/or further development of the group.
- d) To assist parents negotiate access to appropriate integrated generic services.
- e) To liaise with all agencies appropriate to meeting the needs of children with a disability or delay and their families.
- f) To offer support and advice to parents and/or arrange for such support to be offered.
- g) To disseminate information to parents and community.
- h) To develop community awareness and education in respect to persons with a developmental delay and/or disability.
- i) To assist in the development and implementation of parent education programs.
- j) To participate in monitoring, evaluation and service review.
- h) To facilitate co-ordination and communication between groups across the region and within the state.

Over the four and a half years of our experience together, the group has nominated areas of great importance to share with you.

Mutual Support

As children get older, changes in life needs, diagnosis and outlook occur. These can be devastating and throughout all of these cases, the group remains constant. Because of this support system, the ability to maintain the family unit is increased.

Information Exchange

The opportunity to learn about situations before they occur by contact with others who have experience in these areas allows a better outcome for most situations. The practical information gained saves many hours of searching.

Liaison

The group has opportunities through the group process and the co-ordinator working which allow for meeting any people with a service to provide in an informative and friendly way.

Community Education and Resourcing

Parents are available to the community and service providers to offer their experience and knowledge.

Lobbying

Through group experience, the opportunities are arranged to meet decision makers - government and local government people to make them aware of the needs of people with a disability.

Advocacy

This is an important focus of groups work. It covers the needs of the whole family in any setting that a parent feels unable to cope with without a support person fully aware of the issues involved.

Families who have children with a disability are often times experiencing greater stress than the "average" family, eg, increased financial burdens, ill health of the child, extended period of child dependency, difficulty of adjustment of family members. Many parents experience a long grieving period during which they do not or cannot access appropriate services. Many parents also experience a lack of confidence in their ability to cope.

The ill health and delay in the normal life progress of the child is a constant factor and causes the families to be placed in abnormal situations of caring. This ill health may extend to the principal carer, usually the mother, and manifests as low grade and continuous back strain and pain caused by constant heavy lifting, tiredness, lethargy and depression.

The opportunity to have regular weekly contact with other people experiencing similar life problems is very important as it offers the opportunity to exchange knowledge and information they have learnt in the living with disability. Without this regular contact, these families suffer great risk of isolation from the community which adds to the many burdens they already bear.

- During 1988, The Benalla Support Group has worked in close liaison with the Maternal and Child Health Service to offer support to children and their families, identified by the Sister as being at risk of developmental delay;
- Arranged and managed a six weeks "Movement To Music" course with a Physiotherapist specializing in Dance Therapy from Melbourne. This was financially supported by the Benalla Soroptimist Club;
- Negotiated with the Benalla District Hospital for the establishment of an Early Intervention Playgroup on a weekly basis;
- Acted as a resource body for education health and welfare agencies planning new services, and as advisors to current programs acted as an advisor to Wangaratta T.A.F.E. in planning their course for Developmental Disability;
- Negotiated with Community Services Victoria for the provision of an Early Intervention Field Officer for Benalla and Mansfield areas;
- Participated in discussions highlighting inadequacies in services.

One of the highlights for us was in late 1987 when we held an in-service day for grandparents to offer them the opportunity to share their feelings about disability and their sorrow, and to offer suggestions and practical advice on how they can help their families. This was supported by O.I.D.S. and conducted by Jitka Jillich from the Social Biology Resources Centre in Melbourne.

There is no doubt that all the achievements of the group could not have been made without the services of a paid Co-ordinator.

The recognition of the validity of groups of people with a disability by the state, through funding provisions that allow them to employ a worker, is of vital importance.

It gives status to that group, showing the community their value, and with this value comes the opportunity for social justice for its members. No longer can this group be ignored. They have a person who can fight long and hard for an issue when a parent alone would have withdrawn to "lick his wounds".

This group is something special - we are O.K. We know it now because we are here with you all for this presentation. There are many parents just like us who could be here too with a little support.

Our families are more able to cope with our children and are more integrated in our community, and the outlook for children with disabilities in our area has been greatly increased through the hard work of this group of parents.

Please think how parent support groups in your area could help you; whether you are a worker, a parent or a caring citizen. Thankyou.