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### Abstract

The ability of parents of children with disabilities in fostering and influencing community understanding and attitudes is crucial, and this paper argues that the role of parents should be seen as complementary to the specific skills offered by a variety of professionals. It describes some of the problems currently caused by mismatched perceptions between parents and professionals and the great need for parents to receive information and education about relevant issues so that they in turn can take on participative roles as educators. **Keyword: Professionals**

# **PARENT PARTICIPATION: A MODEL OF BALANCED INVOLVEMENT**

*John Paul*

## **Introduction**

The role of parents of children with disabilities in fostering community understanding and influencing community attitudes about *normalisation* is crucial to the successful implementation of this principle. It is generally believed that community attitudes favour segregation over integration. Supportive community attitudes, therefore, will not be achieved overnight by decree but will require a concerted, multifaceted and positive initiative on the part of all parties concerned.

Often underestimated and relegated to non-active roles in the past, parents are beginning to assert themselves as capable of contributing positively alongside the professionals responsible for the various aspects of their child's development. The role of parents should be seen as complementary to the specific skills offered by a variety of professionals at the various stages of the development of a disabled child.

Parents inevitably find themselves at the interface between their child's disability and a multi-dimensional community. They possess a better understanding of the problems, the needs, and the attitudes of each community sub-group because they have to deal with each regularly. Parents, therefore, are better placed to act as agents of change than any other group and offer considerable expertise to the team.

## **The reality**

The *reality*, for parents, is a paradox which can only be described as a mismatch of perceptions of service providers on one hand and parents (and their disabled child), the users, on the other. Because the perceptions of what services are needed are often mismatched, the services offered are frequently inappropriate and real needs are not met.

Janet Boorer in the research report 'A world in which slowness is suspect' (1981, 14-15) expressed this paradox in a more positive way:

'The system' [which provides services to the disabled community] has been geared to serve itself through a bureaucratic preoccupation with capital development and funding, staffing levels and career prospects - all at the expense of intellectually handicapped people.

At the very least the principles [of rights, normalisation, integration and the least restrictive alternative] point the way to the kinds of attitudes and programs which will serve handicapped individuals rather than systems or institutions.

The fact that parents are seeking help because needs are not being met, while at the same time professionals and organisations are seeking increased support to continue providing the same kind of services, reflects the significant extent to which perceptions differ.

Traditional concepts of protection, paternalism and privilege represent the public attitude towards disability which must change if the guiding principle of normalisation is to become the new reality. Meaningful participation, the exercising of rights and independence are the concepts which must be recognised by the community for the transition to take place.

In addressing the problems which stem from the mismatched perceptions of parents and service providers as to 'needs' and the nature of 'services', the need for meaningful dialogue between parents and professionals should be recognised as paramount.

### **Participation rather than education**

The issues raised by parents in submissions to each of the working parties bear witness to the growing lobby which is addressing itself to the cornerstone of public attitude described above. The premise which draws these issues in the area of parent education is, simply, that parent education should involve:

- *increased knowledge base* - learning more about their child's disability through dialogue and information sharing with service-providers (medical, para-medical, psychological, social, behavioural and educational);
- *skills development* in the areas of personal self-confidence, self advocacy and recognition of their own resource value and expertise;
- *'political' education* - learning to work the system, to locate and use the sources of information, services and resources;
- *positive participation* - learning to apply increased skills and knowledge to the decision-making processes at each stage in their child's development;
- *advocacy* - sharing the skills, knowledge and familiarity with the system with others in need of support; and
- *awareness* that the traditional concept of a formalised program of study is inappropriate because of the ongoing experiential resource parents already possess.

With few exceptions, children with disabilities and their families climb on to a merry-go-round of service providers shortly after diagnosis is confirmed. Some become professional passengers.

The nature of the 'needs' and of the services provided, the sequence, frequency and extent of service use vary greatly from one case to the next - but in all cases the perceptions of the parties involved (the referral agent; the parents; the

service provider/s) pivot on an assumption that special needs should be met by trained service providers with specific expertise.

Sometimes forgotten and too often ignored by the 'paternalistic' system mentioned is the belief that parents develop a unique experiential knowledge base because they provide a continuous and ongoing resource for their child's progress.

If parents are denied information and the opportunity to develop skills required to competently verbalise their experiential resource, the benefits of knowledge and experience sharing between parents and professionals will also be denied. The opportunity to apply textbook theory and generalised experience to the unique circumstances of each individual case will be lost and the generalist or classical medical model will prevail to the detriment of progress and unique individual needs.

Alternatively, if parents are provided with appropriate information at all stages, are encouraged to develop observation and communication skills, and are offered the right to participate meaningfully, then potentially, through the agency of their experiential resource, the complementary skills of both parties can work together to apply expertise of a general nature to needs which are unique to each individual child. In addition, parents who participate in this way find that the common ground they share with each professional can serve as a link or inter-professional bridge - bringing together the collective contributions and optimising potential development.

Not all parents would avail themselves of these rights and few would achieve the degree of participation which potentially exists. The role of self-help groups as a source of advocacy for parents who lack self-confidence, understanding or the ability to cope with participation could therefore become increasingly important.

### **Towards a framework for parent education**

Central to the establishment of a workable framework or model for effective parent education is a series of propositions which in effect identify the role that parents of disabled children should or could play in implementing the normalisation principle. These propositions are:

#### **The concept of participation**

It is important to emphasise again the need for facilitative decision-making structures and acceptance of a more positive public attitude by the 'system'. Recognition of the albeit latent expertise which is complementary to that offered by professional service providers is paramount.

#### **The participative role of parents in determining content**

The nature of the programs should promote the training of parents in becoming more skilful and effective participants in decision-making. Some may require [an] overall emphasis, some merely expansion of their knowledge base and others the skills to verbalise.

### **The participative role of parents as educators**

The experiential resource referred to earlier and the ongoing nature of their involvement with their disabled child provide parents with a unique potential to contribute to the education of teachers, support professionals and the school community.

The contributions which parents can make as primary agents and as providers of relevant background information for development programs will be discussed in the sections to follow. Participating parents react and interact with the entire range of people who come into contact with their disabled child. The nature of the relationships which parents form with each and every group will inevitably contribute to the overall success or failure of normalisation.

### **The supportive role of self-help groups**

Already there exists within the community a growing informal network of self-help groups representing the views and interests of disabled children and their parents. The availability and delivery of essential services to disabled children in recent times has suffered from diminishing funds and many of these groups have been forced to abandon traditional 'support' roles in favour of community action, political lobbying and advocacy. This relatively untapped resource offers considerable potential support to families unable to effectively verbalise needs or cope with their problems.

Accepting that 'traditional' education is an inappropriate means of fostering skills, knowledge, self-confidence and participation, it is worth noting the potential role which such a community group might play in the revised approach to parent education. Parent self-help groups have, as their very foundation, a caring, understanding and positive attitude towards the pressures and problems facing families with disabled children. Their involvement in the community is based on that self-same experience.

One of the most common complaints from parents is that professionals seem unwilling to communicate important knowledge or listen to their point of view. Often it is the parent of another disabled child who has offered the most patient listening and the most practical advice.

Parents and parent organisations have had and continue to have much to contribute. Too often, however, the bulk of the work is left to a few energy-drained parents who have no administrative back-up and who are forced to devote excessive time to fund raising activities in order to survive.

### **Advocacy**

Where possible, self advocacy deriving from a successful parent education program is most likely to succeed because unique needs and concerns are best expressed by those affected. Participation, the process from which self advocacy will develop, does not happen overnight - nor will it attract large numbers of parents initially.

Government funding of parent advocacy and, where necessary, advocacy by members of the self-help movement on behalf of parents should be considered as a desirable and cost effective means of providing the balanced model of involvement and ultimately the best interests of disabled children.

### **Author**

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### **Editor's comments**

The Action Group for Disabled Children is a self-help, parent support group which lobbies for services and facilities to disabled children, and also promoting the rights and needs of disabled children.

The Group has more than a hundred financial members throughout Australia and this membership consists of parents of disabled children, relatives and friends, social and community workers, doctors, and therapists. Although the Group is not affiliated with any other society or organisation, it co-operates closely with other organisations on matters relating to children and disability.

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