In many countries around the world, services for children and adults with developmental disabilities have come about because of the efforts of parents. In Europe much of this began in the 1930s.

In this, as in many other respects, developing countries have lagged behind. This may be partly because a larger segment of their population has been disadvantaged in other ways which put disability as a low priority. There is more poverty, services of all kinds are fewer and they are less accessible. The dependency of Third World countries at the national level reflects their dependency at the individual level. Consequently advocacy efforts are stifled.

There is probably more ignorance and shame about disability because the population at large have not been exposed to relevant and accurate information. Nor are they aware of the newer trends particularly those relating to rights of persons with disabilities.

Since 1980 however, the parent movement in the Caribbean has gathered strength, especially in relation to families whose children have a developmental disability. To a great extent, much of this change has come about because of the sharing of experiences and training facilitated by the Caribbean Association on Mental Retardation and Other Developmental Disabilities (CAMRODD) from 1970 onwards.

As professionals working with developmentally disabled children in Jamaica, the first and most obvious gap seemed to be the lack of services to families at crucial times, such as at diagnosis, at school entry, adolescence and later adulthood.

Much progress has taken place since 1970 in special education (CAMRODD, 1990, PAHO, 1993), but there are still a large percentage of children with disabilities who have not derived any benefit from the educational system. The rights that are automatically accorded to the non-disabled child are not extended to the disabled child, even at the individual level, in their own homes by their own parents.

Further, rights to basic services such as health care and transportation, are frequently denied to mentally retarded persons who are regarded as low priority and not worth the effort or expense. The list of situations that discriminate against persons with disabilities is long and includes many aspects of everyday life, such as access to buildings, schools, transportation, houses, religion, voting, insurance,
driving, even the home itself.

**Parent Participation**

Prior to the economic, oil-related crisis in the seventies, it seemed that Caribbean governments might get involved more actively in services. Unfortunately, by the end of that decade and in the early 1980s when structural adjustment policies began to bite, it became apparent that if anyone was to do anything for children with developmental disabilities, the parents would have to be in the forefront, not only as caregivers but as organisers. In spite of this, little emphasis has been given to parents and their needs even in the voluntary organisations.

Numerous barriers to parent participation exist in Third World countries. But during the past 10 years we began to realise that mobilisation and training of parents was not only desirable for sustaining services to children, but it was essential if these children are to have a secure foundation for becoming contributing citizens to their society. As Bronfenbrenner (1974) notes,

*The involvement of the child's family as an active participant is critical to the success of any home-based, intervention programme. Without such involvement, any effect of intervention appears to erode fairly rapidly once the programme ends. In contrast, the involvement of parents as partners in the enterprise provides an on-going system which can reinforce the effect of the program while it is in operation and helps to sustain them after the program ends. (p. 4)*

As in many aspects of Third World developments, there has been very little written about the involvement of parents, though many people have experience and can cite anecdotal observations. Generally speaking however, many professionals in developing countries still regard parents as part of the problem rather than part of the solution and often act in a paternalistic manner to them. The medical model frequently prevails with its focus on 'the doctor knows best'.

This chapter traces the evolution of the voluntary and parent movement in Jamaica. Drawing on examples from the Caribbean, we will show how parent training and the intimate involvement of families in community based services has resulted in more participation by relatives, the benefits it has brought to families and the leadership roles now undertaken by parents. The process, and the progress however, is slow.

**The Challenges of Working with Families**
At present, many people who are exposed to children and their families, are witnessing a crisis in parenting. The family has become split apart and shredded, leaving many children to find their own way, or even to take on a role in economic support. A response to this situation is getting under way, but do we have enough people to take a leadership role in such a dismal situation? And where is the child with a disability in all of this?

**Child Rearing Styles**

A long-standing feature of child rearing in Jamaica (Grantham-McGregor, Langman and Desai, 1983) as well as in other parts of the English-speaking Caribbean, is the use of punishment as a tool in discipline and learning. These researchers concluded that:

> A picture emerged of a rich social life and authoritarian discipline, with little conscious encouragement of play or verbal interaction. However, at the same time, emphasis was placed on formal schooling. The children's level of development was related to levels of stimulation in the home. (p.69).

Similarly in our experience of conducting workshops on managing behaviour problems, two popular beliefs were 'spare the rod and spoil the child' and 'children should be seen and not heard'. Such beliefs extend across all social groups. Middle class children are often reared by domestic helpers while their parents are out working long hours. The situation described above may well apply in this group, although they will certainly have more toys and appear on the surface to be better off.

How does this affect the child with a disability, especially those who have problems in learning? It seems very likely that they will be subjected to punishment even more frequently and because of their slow learning, they will be written off as a future investment; being denied their fair share of the pie.

Another feature, specifically relating to childhood disability, is over-protection. This may occur because the parent feels guilty or sorry for the child and tries to 'make it up to her'. Such over-protection and over-indulgence in turn, stultifies the child's desire to become independent. Such parents may be very loving towards the child and give excellent care, but they tend not to participate in training in the home (Terwindt, 1992).

An opposite response is for the child to be neglected and discriminated against. If money is short in the family, what is available will go to the able-bodied children. Those with disabilities,
may have poor attendance at school; being left at home alone.

Finally, the child's problems may reach a crisis stage, where the family can no longer tolerate the child's behaviour or when he or she becomes too big to be moved around. This usually happens when there have been no services available during the preschool period and the problems have got worse instead of being prevented or resolved at an appropriate time. In some cases, the parent seeks an institutional placement as the solution to their problem.

**Traditional Beliefs**

Aside from poverty and lack of education, many parents who had the capability of leadership do not come forward as one might have expected. Since parents of disabled children come from the same cultural background as the society in general, one has to examine the attitudes and beliefs of the people of the region to understand this phenomenon.

Most societies have traditional beliefs on many subjects. In the case of childhood disability there are two main areas that affect families; first, beliefs about the causes of the disability and secondly, misconceptions about the effects of the disability and the child's needs. Some of these beliefs are detrimental to the child in that they are not only hurtful and unpleasant for the parents - affecting not only their attitudes and child rearing practices - but they are also counter-productive. For instance parents may not want to take part in a home based programme as they do not think it is relevant or because they are waiting for a miracle to happen.

**Community Perceptions of Disability**

In 1993, 3D Projects carried out a study of knowledge, attitudes and practice in three areas in Jamaica (Thorburn, 1993). The findings are of interest, especially in relation to two previous qualitative studies carried out in 1987 and 1992. These had indicated that some of the main parental experiences which militated against parent involvement included lack of a supportive family, poor experiences with services at the time of discovery of their child's disability, misunderstanding of the nature of disability and the scope and possibilities of rehabilitation (Terwindt, 1992).

A stratified survey was conducted in June, 1993 in the parishes (i.e. districts) of St. Catherine (Spanish Town and Linstead) and St. Mary, with 300 persons in each area, made up from five age groups (15 to 59) and twelve occupational groups with a minimum of 30 in each group.
The questions in the questionnaire were divided up into five main categories:

- Supernatural beliefs
- Misconceptions about behaviour and expectations for people with disabilities
- Denial of human rights
- Feelings of competency and willingness to help people with disabilities.
- Knowledge about disability services

Supernatural beliefs were held by a significant minority, with negative beliefs less prevalent (18%) than the idea that disabled children are "sent by God" (40%). These beliefs are significant if held by parents, because they may interfere with intervention efforts or may encourage isolation and "putting away the child".

Perhaps these are also the reasons for some of the most pervasive misconceptions, i.e. the preference for special schools and special homes. The supernatural beliefs were associated significantly with age (the youngest and the oldest age groups) and with low-income occupations.

Fortunately, the positive assertion by 96% of respondents that programmes should be shared by the government and the community - only 25% thought that the government should have full responsibility - was borne out by the expression of personal willingness to help a neighbour or a person having a fit or to volunteer if training was provided. These have an important bearing on the development of community based services and the involvement of parents.

In conclusion, the main barriers to community integration were seen to be:

- some persistent supernatural beliefs;
- the lack of awareness of the possibility that community and home based services can be effective;
- the persistent belief that special institutions are best;
- the lack of recognition of some human rights, particularly to full participation, integration and equality of opportunity.

The big plus however is the generous willingness of the community to help.

**Evolution of the Voluntary Movement**

There have been two main phases in the evolution of the voluntary
movement in both Jamaica and other Caribbean countries; the period before 1970 and the decades afterwards. The watershed of 1970 saw the shift from very small, charitable efforts in a few of the countries to more wide scale programmes, some of which were supported by the governments of the region.

The events that occurred at various stages in the region and Jamaica were mutually reinforcing. The turning point in 1970 began when the countries of the region met together for the first time to discuss 'Mental Retardation: Needs, Resources and Approaches'.

In four countries of the region who already had a few schools for deaf, blind and mentally retarded children, more voluntary associations were formed and short term training began under the auspices of the Caribbean Association on Mental Retardation, later to become Caribbean Association on Mental Retardation and Other Development Disabilities (CAMRODD). CAMRODD'S bi-annual conferences have enabled people working in the field to keep up-to-date with new developments.

In 1975 the Caribbean Institute on Mental Retardation (CIMR) was initiated by CAMRODD as its technical and resource development arm. From there on, there has been augmentation of existing services and the development of new ones, especially in the areas of early intervention and vocational rehabilitation (CAMRODD, 1990; Thorburn and Houston, 1990). Leaflets and booklets for parents and community workers were developed for use by the various organisations in the Caribbean.

Another important development was initiation of training courses in special education in teacher training colleges made possible through technical assistance to the Government of Jamaica by the Netherlands Government. In fact this was a three pronged approach; as well as teacher training, special education units were built in primary schools and the Centre for Assessment and Research in Education (CARE) was established in 1980 as a specialised programme of Mico Teacher Training College.

Until 1990, most of the emphasis was on service development and professional workers and quite rightly so in our view. Our experiences in trying to establish parent groups and community based services in Jamaica where services were absent or minimal were unsuccessful at first. We found that parents would not come to meetings, training or join in supportive efforts until their own basic needs for themselves and acceptance of their children were being met.

Since 1988, CAMRODD began to shift away from service development to a stronger focus on parents, and particularly on their leadership.
The Jamaican Experience

Family involvement had been taking place in Jamaica since 1975, when a home-based, early intervention programme was started in Kingston (Thorburn, Brown and Bell, 1979). This focused on the mother or care-giver training the child. The curriculum used was an adaptation of the Portage Programme (Bluma et al., 1976) and families were supported and guided at home by a specially trained and recruited community worker.

During this project it became apparent that first, parents themselves needed more education and training and second, that being a parent of a child with a disability was an asset to the work of those acting as community workers.

In 1980, for the first time, we deliberately selected parents as our Community Workers and at the end of 1982 when funds for the St. Catherine Early Stimulation Project ran out, the St. Catherine Parent Association for Disabled Persons kept the project alive. From 1983 to 1984 the Association took part in a parent training project held in four different main towns of the parish. In each area between 20 and 30 parents and other interested persons took part.

The objectives of the training were:

- how to get services for their children;
- how to work together as a group;
- how to stimulate maximum development in their children;
- how to learn skills for greater economic independence.

All of these objectives were met and a more vibrant parish association developed, though attaining the first objective has taken a longer time than we anticipated.

At their annual general meeting in 1984, the parents voted to rekindle the home visiting programme but this time it was decided that it should address the needs of all types and ages of people with disabilities. The outcome was a new community based rehabilitation (CBR) programme.

Another outcome of the parent training was an excellent selection and recruitment process for the CBR project workers. All were identified during the training courses.

This experience in 1983 to 1984 led us to realise and articulate some basic issues that needed to be addressed if we were to be able to get parents involved.

1. We must adjust our approach from a centre-orientated, inward view to an outgoing, community orientation.
2. We must be responsive to the perceived needs of people and not impose our own view.
3. Disability is often associated with poverty and poor people are usually poorly informed and lack influence.
4. The stigma of disability isolates them from family and community and discourages them from seeking their rights.
5. Disability may create an additional burden on an already handicapped family and they quickly become apathetic and "burnt out", especially as services are lacking or inaccessible in "user-unfriendly" systems.

The above insights may seem pretty obvious now but they were written eleven years ago (Thorburn, 1984).

**TABLE 1: PARENT ORIENTATION COURSE OUTLINE**

*This is the outline of a 10 day parent training course in orientation to disabilities designed by 3D projects Ltd. It has been used successfully in Jamaica and in other countries over a number of years. The main topics covered are:*

**Day 1:** Parent-child relationship; situation of disabled children in Jamaica and the world; barriers to development of services; attitudes, misconceptions and beliefs; early signs of disability.

**Day 2:** Normal development and what can go wrong; need for screening and use of screening tests; disability and handicap - definitions.

**Day 3:** Prioritising handicaps; recap on screening; actual use of tests on children; nature and behaviour of mentally retarded children; seizures (a doctor should participate here).

**Day 4:** Learning problems; more on signs and effects of mentally retarded children; play as an aid to development; simplified methods of teaching these children.

**Day 5:** Group work - designing play programmes for participants' children; orientation to employment possibilities for mentally retarded persons.

**Day 6:** Motor problems (a physiotherapist should lead this day's session); types and effects of physical disabilities; group work - examination of children to determine their problems; cerebral palsy; independent living for disabled adults.

**Day 7:** Behaviour problems; reasons for children's behaviour; parental attitudes; use of drama by parents.

**Day 8:** Speech and hearing problems (a speech therapist should
participate if possible), what parents can do to help each other.

**Day 9:** Familiarisation of parents with programmes in their areas.

**Day 10:** Review of course and plan for further action; discussion on the main needs of disabled people in the community; resources available in parent group and their community; skills bank - set up registry of what each person can contribute.
Regional Developments

The Jamaican developments began to influence other countries in the region through conferences and seminars which in turn stimulated the development of similar programmes in Belize, Trinidad and Tobago, Grenada (Thorburn, 1986; 1990), and more recently, in Antigua and Dominica.

This growth in turn influenced CAMRODD which began a new thrust, with the help of the Canadian Association for Community Living and the Roeher Institute in Toronto. The focus was on leadership development as outlined in the mission statement "New Trends for the 21st Century" (see Table 2). This "Blueprint" and the accompanying statement on rights and goals in five different aspects (education, the home, parent and public education, services and employment) has been a fundamental feature of all our training programmes since 1991. We have found that the Blueprint serves as common ground for training parents and professionals and for research.

Parent Participation in Voluntary Organisations

Prior to the advent of some of the efforts described above, parent involvement in the work of many of the voluntary associations in the Caribbean region was not very evident. The process of empowerment had only just begun. The Blueprint was introduced and incorporated into a regional leadership training programme conducted by CAMRODD, which was begun in late 1991. By the end of 1992 we had a corps of parents who were prepared to act as change agents in their countries. 1993 saw the parent leadership training taking place in Jamaica and a new cadre of empowered parents and workers in the field evolved. To complement this, CAMRODD has begun a new phase of training in partnership with the Norwegian Association for the Mentally Retarded, which has provided three day courses for groups of parents in 12 different islands in the region. The topics covered are chosen by the parents' groups themselves, but the purpose is to encourage the formation or development of parent groups (see Chapter 9).

Voluntary Associations and Provision of Services

As remarked earlier, although there has been an active voluntary movement in the Caribbean from the early 1930s, these organisations, with one or two exceptions, have been or became charitable organisations. In spite of the sterling pioneering work,
their main missions inevitably were paternalism, segregation, pity and dis-empowerment.

Parents, and even more so the persons with disability themselves who started to speak out for their rights, were regarded as trouble makers. In one country, during the International Year of Disabled Persons, the national committee almost had to resign in order to get the government to agree to have a person with a disability as the paid co-ordinator for the year.

**Normalisation**

In the early 1970s, normalisation and integration was the gospel according to Wolfensberger (1972) who described three stages in the evolution of voluntary associations for the 'mentally retarded'. These were:

1. Providing services
2. Obtaining services
3. Advocating for social change

One of his dictates, which has haunted countries of the region, was that voluntary associations should reject the temptation to provide services. The dilemma is, if we don't, who will? Nearly all the original voluntary associations submitted to the overriding need as they saw it. But it led to what Wolfensberger had predicted; getting bogged down in fund-raising and administration and omitting to satisfy the many other needs of parents, particularly for support and information. As a result, during the late 1970s, new organisations of parents erupted and challenged the status quo. Even so, it has only been in the last seven years that CAMRODD has really responded to the need to fully empower parents.

At the same time, it is also necessary to inform professionals - gently but firmly - of a more preferred role, that of support rather than service. This means shifting from what has been called the 'medical' model to a compensatory one where the person being helped is fully informed of the options, is encouraged to make their own decisions and fully participates (or not) in their chosen intervention (see Chapter 2).

**Parent Empowerment: How does it happen?**

The process of deliberately developing parent empowerment in the disability field probably began in 1990 at the 10th Conference and 20th anniversary of CAMRODD, although the planning started earlier in 1988 when the CAMRODD Executive Committee decided
to begin the leadership development programme.

Through a "grassroots" approach of having a series of subregional meetings, in three different countries in two rounds, the "Blueprint" was conceived and delivered (see Table 2). The workshops were basically a lot of parents and other interested persons coming together to brainstorm about their vision for the 21st century. Their dreams, their hopes, their problems were all taken down verbatim, and from that first account, they were analysed, pulled into shape and re-drafted for the second round of workshops.

The process of empowerment might not have happened so quickly in this way if it had not been for the fact that many parents who took part in the "bottom-up" planning of the Blueprint, had already been exposed to training from 3D Projects and were very well equipped with knowledge and skills.

Also, during this process, a number of these people stood out as being particularly articulate and some of these were invited by CAMRODD to participate in a leadership development programme. This began in November 1991 with three separate, one week training courses, finishing in April, 1992. By the time of the first course, the distillation of the fledgling "Blueprint" was completed and by the second course, it was printed and available for the leaders to use.

Since then, it has been used as a basic text for all courses in the region and it is also given to many influential persons throughout the region. Sometimes a whole day is devoted to it, sometimes a couple of hours; the longest was three days. The most impressive occasion was during a CAMRODD parent training course, where three government ministers attended the opening and stayed on for two more hours to discuss the Blueprint!

Of all the topics that are included in training workshops, we regard the Blueprint as the most powerful in enlightening and empowering participants. However, it cannot stand on its own. Other issues need discussing; the dispelling of myths and misconceptions, and the sharing of bitter experiences which leads to solidarity. Knowledge is power and parents, once attuned to the process, have insatiable appetites.
TABLE 2: OUTLINE OF CAMRODD'S BLUEPRINT

The Purpose:
The Blueprint outlines an agenda for action.
1. To define together goals, objectives and strategies for the Caribbean Region;
2. To develop a sense of Mission - A new organisational approach now and for the 21st century;
3. To identify and train accountable leaders in the CAMRODD community.

Our Dream:
Is that every individual with a disability takes his/her rightful place in the society of his/her respective countries; that every individual with a disability be treated with dignity and equality and be given the opportunity to develop self-respect.

Our Goals:
In order to realise our philosophy and our dreams, we will work towards specific goals in the areas of:
- Education
- Home
- Parent and Public Education
- Services
- Employment

NB. Specific goals are then outlined for each of the five areas.
The acquisition of competence in skilful handling of their own and others' children is also very empowering. As a result of this newly gained knowledge, skills and changed attitudes, we have found that parents speak out for themselves against discrimination, paternalism, talking down, or being dismissed without an explanation by professionals who think that they cannot understand. Many of our parents now realise that they know more about childhood disability than many professionals.

Future Developments

In spite of all the above developments, parent advocacy is only just beginning and it has a long way to go. We perceive a problem area which relates to the bipolar social structure of Jamaican society, with its diverse ethnic make-up and racial stratifications, where light and white skinned people are mainly in the upper income brackets and those of darker hue in the lower. It is the latter who have become empowered in spite of their limited educational opportunities. The other group, potentially more influential in seeking and making changes, have not been involved in the advocacy process and their concerns mainly focus on their own children's needs. They lack vision in the larger picture. This group now badly need to be educated and become more active in a movement which has a unified view of what is needed at the macro-level. Then all their children can be accepted and take their rightful place in society.

References


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