



# A bundle of sticks<sup>1</sup>:

*Family Based Organisations in Developing Countries*

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## **The Facts**

- Nine out of ten people with an intellectual disability are estimated to live in what is termed 'developing countries'; the 'third world' or 'non-industrialised' nations (Helander, 1993).
- At best, one in ten of these folk will receive any form of assistance from outside their family. All are dependent on their family for help and support (Mittler, 1994).
- Most of their families live in poverty; either in urban slums or they depend on subsistence farming. Most die young (UNICEF, 2000).

What a difference a century can make! These facts were just as applicable to North America and Europe some 100 years ago. The growing affluence of so-called Western nations is only part of the explanation for the well-developed service structures that exist today. Indeed up to a generation ago most of the monies in

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<sup>1</sup> *Gwen Glasgow, a parent activist in Guyana South America uses the analogy of a parent association as a bundle of sticks. One stick, just like one parent may easily break but when they come together as a bundle, they cannot be broken.*

these countries was spent on institutional care with most professionals recommending this option as being best for both the 'mentally retarded' person and the family.

Why the change? Parent power has been a major influence. In many countries the growth of new styles of community services began with a small number of parents demanding a better deal for their children. They wanted to keep their son or daughter in the family but in return, they argued for the provision of schools, day centres and financial benefits. They tried to persuade professionals and government administrators and when they did not succeed they started their own services. For parents, it was an issue of equal rights and opportunities, although most would not have labelled it in these terms. It was their flesh and blood for whom they advocated; not a handicapped or retarded 'case'.

To them too, fell the task of changing society's attitudes. The shame and disgrace of having a deformed child was keenly felt as common explanations revolved around old superstitions and punishments for misdeeds; usually by the mother (Ingstad, 1988). It took guts to be seen in public with your child; still more to speak up for their rights. But as a few challenged conventional mores, others then joined the cause, aided and abetted in time by a growing array of sympathetic professionals in health, education and social services along with a host of volunteer helpers.

By definition, the pioneering parents were exceptional people. They tended to be better-educated, articulate, affluent and well-connected in society. And although motivated to get the best for their child, they argued for a better deal for similarly affected families. Invariably they came together with others to share experiences and to join forces in making their views known. The parent association was born.

In many countries, as the membership grew in numbers, local branches were formed; new initiatives were undertaken and in time politicians and governments started to listen and even consult with them about future policy.

Of course, such developments never ran smoothly. Branches split away from the national association because of disagreements; office-bearers stole money; associations disbanded through lack of interest; new groupings emerged for specific

syndromes and competed for members with longer established associations who had an aging membership. As they say, all human nature was there!

Today, I suspect that the power and influence of parent associations in most developed countries has waned and been supplanted by professional expertise and experience. Indeed some may judge that was always the case. But either way, parent associations have been a most vital influence in the development of services. And while they are part of history for affluent countries; they are the future for poorer countries.

In this chapter, I will examine the various role families - but women in particular- play in supporting the person with intellectual disabilities through their life-span. The form and functions of parent association are outlined with a particular emphasis placed on parental empowerment. Finally the main challenges are outlined for services in developing countries.

A word of caution needs to be entered at the outset. Rarely have parent associations been systematically researched in developed countries; still less in the developing world. Hence the dangers of relying on the vagaries of subjective opinion need to be borne in mind plus the risk of presuming that experiences in one culture are applicable to all.

## **Women's work**

In most societies of the world, the task of child-rearing and caring falls mainly on women, usually mothers but also on grandmothers and other daughters (Bornstein, 1991). (However, for sake of convenience the term mother is used throughout.) Arguably there are four main roles that mothers fulfil in relation to the disabled child or dependent adult.

1. 'Children first, disabled second' is more than a slogan. It is a service philosophy too easily forgotten by disability specialists. For many families in developing countries their immediate need is not for aids and appliances to help the disabled member, rather it is for clean water, sanitation and basic health services (O'Toole, 1995). Unlike rich countries, the major causes of intellectual disability in these countries are childhood illnesses such as measles and cerebral malaria (Rublin and Davis, 1986). To mothers often falls the task of keeping her family fed and healthy.

2. Mothers nurture the child's intellectual development. This may be through one-to-one attention in tasks such as feeding and dressing or through family games and activities. Often it is mothers who seek out nursery and school placements and assist with home-work. With the disabled child it is they who will attend clinic appointments and who are expected to carry out recommended therapies at home (World Health Organisation, 1985) .
3. Mothers also have an important role in socialising the child into the wider community. First by bringing the child to community events such as religious ceremonies and celebrations but also by encouraging friendships with peers and relatives. Implicit in this is an inculcation of moral values and conduct (Gartner, Lipsky and Turnbull, 1991).
4. The provision of emotional support through close, sensitive and loving relationships between mothers and children will do much to foster their self-confidence and self-esteem; providing the child with a much needed sense of security and safety (UNICEF, 1989).

In addition, mothers have to fulfil these roles alongside the other demands placed on them – working in farms or factories; coping with household chores; caring for ageing parents; and being a wife to their husband. Moreover it is a tribute to the resilience of human parenting that most mothers manage all these roles despite famines, wars and poverty that beset many lives. A child with a disability may be the least of their worries and can even be a solace amidst their woes (Mittler, 1994).

The fact that most mothers and families cope is not to imply that it is natural or easy. The sacrifices are many; not least in terms of self-fulfilment; and poorer physical and mental health of mothers. Yet despite attempts at finding other ways of bringing up children, the best alternative to natural families is undoubtedly another family. Hence the rediscovery in the West of fostering and adoption rather than children's homes and residential schools no matter how well these are staffed and resourced. It is a salutary reminder to all professional workers of the limitations of their expertise and influence in the lives of children. At best their essential role must be to support families in their child rearing and child caring responsibilities that in the case of persons with intellectual disabilities may extend far into their adult years. Yet even this may take second place to the support mothers receive from their

partners; extended families; neighbours and friends which in developing countries is often the only support that is ever likely to be available.

In sum, mothers are irreplaceable but they need and deserve support if they are to be sustained in their roles.

## **Parent Associations**

In many countries around the world, this support has come primarily from associations formed and organised by parents. Although varying in size and sophistication, these associations commonly fulfil three main functions; providing parents with solidarity, information and advocacy.

**Solidarity:** The heart-ache that comes from feeling alone with a problem can be assuaged by meeting others who have been through or who are going through similar experiences. Equally it is easier to join others to challenge prevailing attitudes and practices in society rather than to take action single-handedly. Membership can also boost self-confidence and help to create a sense of pride in having a child with disability. This appears to be best fostered at a local level; hence national associations need to develop a network of branches.

Solidarity can also be nurtured internationally through Regional groupings of national associations as has happened in Asia-Pacific region; the Caribbean and in English speaking Africa as well as through world-wide organisations such as Inclusion International which claims links with 20,000 associations of families and self-advocates.

**Information:** Parents bemoan the lack of information that is available to them even when they have access to a range of professionals (Chen and Simeonsson, 1994). Often the need is for information that is tailored to their present needs and concerns and presented to parents in readily accessible ways. In Lesotho, southern Africa, the leaders of nine branches linked to the national parent associations identified the following needs for their parents (McConkey and Mphole, 2000):

- Knowing how to assess, teach, train and handle their child
- Ways of raising parental awareness and of mobilising parents
- Rights of people with disability
- Disability issues generally
- Working alongside professionals, report writing for committee members

- Making teaching aids and equipment

Parent associations often produce newsletters for their members; most organise meetings, conferences and training events with invited speakers; some have telephone help-lines and other employ 'parent advisers' or development workers to provide information and training for their members. Russell, John and Lakshmanan (1999) demonstrated the gains to families in Southern India of participating in ten weekly group-based sessions that provided information on a range of topics.

**Advocacy:** National associations have a vital role to play in speaking up for the rights of people with disabilities. Indeed the first declaration of rights adopted by the United Nations for disabled people, was that for Mentally Retarded Persons in December 1971 following lobbying by the then International League of Societies for Mentally Handicapped Persons (now known as Inclusion International).

Parent associations often organise events to profile issues of concern and gain the interest of media such as radio and newspapers. Delegations from the association may also meet government officials to press their case. Likewise, the national association may support individual members as they confront local issues, such school enrolment or police refusing to prosecute a rapist of a lady with intellectual disabilities.

The advocacy role is likely to be more effective if alliances are made with other organisations who share a common interest; most notably organisations of people with disabilities. In many countries there is now some form of national disability council that brings together all the disability organisations.

## **Models of Parent Associations**

### **Empowerment Model**

These three functions of building solidarity; supplying information and promoting advocacy are all summarised in the concept of *parent empowerment* which some would see as the pre-eminent function of parent associations (Skogmo, 1995). This model of parent association has certain implications. The management and control of the association rests solely with parents; professionals can only have a supportive role. Associations must grow indigenously; they cannot be imposed by governments

or by professionals or from outside the country no matter how well meaning the donor agency is to develop services for parents.

Of course other models do exist and indeed the empowerment model is not without its critics, notably from organisations of disabled people who are concerned that the wishes of the parents are promoted above the rights and needs of the person with disabilities themselves and opportunities are stifled for them to speak up for themselves.

There are two other models of parent associations.

### **Service Model**

In many countries, parent associations have gone on to organise services for their members and for other families who have a child with disabilities. Most often these have been day centres and schools for children and sheltered workshops for adult persons. However others have launched preschool home visiting services, supported employment schemes and residential facilities. Often these were developed as 'model schemes' with the hope that they would be taken over or emulated by government which has indeed happened in many instances.

However these endeavours do produce a very different model of association. Greater priority has to be given to fund-raising with a consequent danger of perpetuating the charitable image of disabled people rather than promoting them as members of society with equal rights (Bersani, 1998). As more paid professional staff join the association, power and influence can slip away from parents as they defer to those with training and expertise in disability such as doctors and therapists or those with backgrounds in financial and personnel management. The organisation can shift away from addressing the needs and concerns of parents towards an agenda set by staff and the funding agency.

Two broader risks are also present. The services are more likely to be available to the more affluent, better educated, urban based families; especially if charges are levied for using the service. Secondly, government agencies are given the perfect excuse for not developing services or making mainstream services available to those with disabilities, namely that special services are already doing the job.

In reality, parent associations invariably end up providing some service and it can hardly be otherwise when the needs in some countries are so great. Often this takes the form of food distribution and clothing; the provision of medicines or aids such as wheelchairs or the development of income-generation schemes for mothers. In more developed countries, leisure schemes and holiday breaks for member's relatives are common as these forms of services are unlikely to receive government funding or require professional involvement. However knowing what NOT to do is as crucial for the future well-being of an organisation as is knowing what to do.

### **Partnership model**

The advent of community-based rehabilitation (CBR) schemes has given rise to another model of parent organisations (Helander, 1993). Given the lack of professional expertise in most developing countries, CBR schemes rely on training a cadre of support workers who in turn train family carers to provide the necessary therapy, training and education of the person with a disability. Although CBR programmes were initially conceived as being led by professionals who instigated the training and support of the support workers, more recently the emphasis has shifted on to building community ownership of local schemes (O'Toole, 1995). Local management committees are established consisting of family members, community leaders, interested community staff such as teachers and health workers and disabled persons. They take responsibility for different aspects of the CBR programme such as the support and training of families, provision of resource centres; community education initiatives and the development of community facilities that promote the well-being of everyone in the community. Likewise in parts of China, neighbourhood resident committees undertake some of these functions as part of the Welfare system (Tse, 1995).

This model brings together families and people with various disabilities, unlike the previous ones that tend to concentrate on a specific disability. Moreover relationships are forged among the various stake-holders; membership is not confined to parents. However these schemes are invariably localised – often based in rural areas - as it is difficult to replicate this model at a national level. Instead a national federation of local CBR schemes that retain their autonomy holds promise as a means of attaining a national voice and profile.

In sum the tensions among these three main models of parent associations are likely to persist for sometime within developing countries although in the developed world two trends are becoming clear. First, parent organisations are including persons with intellectual disability as full members and consequently shifting more towards an empowerment rather than service model. Secondly a partnership model is becoming more remote as associations for more specific disabling conditions proliferate; each intent on ensuring that their particular demands are met. The consequences of both these trends will become apparent in the years ahead.

### **Challenges facing developing countries**

The world's poorer nations face some particular challenges that modern technological society struggles to understand and which can be easily overlooked. These are listed here with some possible solutions.

#### **Reliance on international donors**

The amount of monies that parent associations can raise locally is often inadequate for them to develop the infrastructures to meet their members' needs nor will their governments contribute to these costs. For many groups, the solution has been to seek donations from abroad although this has often compromised their autonomy and means of working. International funding agencies need to develop more equal, trusted relationships with the groups whom they fund (Brohier, 1995).

#### **Government prohibition**

In some countries, the formation of associations is deemed unlawful and perceived as a threat to government. Official sanction may be obtained for associations to be formed although this may be at the price of being a tool for the 'party' or government. Another alternative is for groups to meet under the name of social club and ostensibly to eschew any form of action that could be construed as political. Finally in some cultures, men may not allow their wives to become involved with associations and they can also prevent visitors coming to the family home. Progress in these domains will only come about through wider cultural changes and democratisation.

## **Communications**

Telephone, fax and electronic communications are still sparse in many countries, certainly outside of the major cities. Likewise road transportation can be poor and even non-existent. O'Toole (1995) recounts how a husband and wife travelled ten days by canoe and on foot to attend training workshops in the Amazonian forests.

Satellite communications and modern information technology offer some hope but often dependable electrical supply is the greater problem. Again, as the national economic prosperity increases, these issues will fade.

## **Leadership**

The initiative to form and maintain parent associations often comes from a few exceptional parents. The danger is that these same persons are likely to be the ones who will move on to fresh challenges. Hence the continuity and expansion of associations depends on developing the leadership skills of the membership. In Lesotho for example, the national association organised training for committee members of branches in skills such as training, chairing meetings and community awareness raising (McConkey et al, 2000). Likewise in USA, Canada and Britain, there is increased interest in training parents in policy-making and how they can influence service systems and practices (Barenok and Wieck, 1998).

## **A.I.D.S.**

In many developing countries but especially in Africa, AIDS is taking a heavy toll on families leaving many children orphaned and in the care of ageing grandparents and relatives. Among these are teenagers and adults with intellectual disabilities who will require life-long care yet who will provide it? The full impact of this tragedy has yet to be felt and may never be fully known. The hardships and misery for these families and their dependants will only be alleviated through planned and sustained programmes but it is doubtful if the political will is there to pursue such goals.

## **Residential Care**

The option of moving away from the family home into other forms of care situations is an option for few people in the developing world. Nursing homes, shared housing or supported tenancies may be available but only for a few and for those families who can afford it. As medical advances impact on developing nations; increased

longevity will surely result yet who will care for adults with intellectual disability who outlive their carers? And even if relatives do continue with the caring, can they manage those with severely challenging behaviours or mental health problems such as dementia? The pragmatic solutions sometimes used of locking people in huts or tying them to posts to prevent wandering or self-injury are hardly practices we can condone. It is hard to see a resolution to this particular challenge that taxes parent associations all over the world.

## **Common Challenges**

There are other challenges that developing countries share with their sister organisations in more affluent countries.

### **Involving fathers**

Invariably women have been to the fore in instigating and managing parent associations. A common complaint is the lack of support received from fathers. In part this may be because professional services have tended to relate more directly with mothers although it is likely also to be reflective of wider cultural ethos in which child-care is predominantly women's work (Herbert and Carpenter, 1994). This has undoubtedly weakened the impact of parent associations especially in their dealing with male-dominated politics and governmental systems. Few solutions have been found although there are notable exceptions from around the world; so it is perhaps too soon to give up on the male of the species!

### **Redefining families**

As the incidence of divorce rises, so too does the number of single-parent families (Kwok, 1995). Likewise the number of children living in reformed families is increasing as parents remarry. Moreover with the breakdown of the extended family, parents come to depend on support from their friends who may become more part of the nuclear family than the child's blood relatives (Carpenter, 1997). The impact of these world-wide social changes on parent associations has not been studied but a pragmatic response would be to ensure that membership of such groups is welcomed from all those who are playing a 'parenting' role.

## **Aging Associations**

Many associations were started by parents who have young children. As their sons and daughters grow older the needs and interests of the membership change. In time, it can mean that the association is no longer seen as relevant to younger parents and so the association or branch 'dies out'. Equally aging parents may no longer be able to play an active part in associations. This may mean that pertinent issues for this group are not addressed. One solution is to try and enlist the adult siblings of the people cared for by aging families although to date this does not appear to be happening to any great extent (Krauss et al, 1996).

## **Priorities for Developing Countries**

In this final section we examine four priorities for which parent associations in developing countries need to advocate and support through local action. These hold the promise of giving people with intellectual disabilities and their families a fuller and productive life.

### **Early intervention from the first months of life.**

The growth and development of infants with intellectual disability needs to be stimulated through regular exercises, activities and involvement in family routines. The impact of early intervention programmes is well documented in affluent countries (Farran, 1990) and there is every reason to believe that similar interventions will be equally effective in poorer countries despite the extra economic and social stresses these families face (Zinkin and McConachie, 1995).

Home visits by trained personnel – albeit of short duration – have proved both popular and effective with families. The 'visitors' could be existing personnel such as community health workers, or volunteers as part of a CBR programme. However disability services in Jamaica, the Philippines and South Africa have recruited and trained parents who have a disabled child for this role. Not only are they from the same culture as the families they serve but they can draw on their personal experiences in advising others.

## **Education**

Although the world's nations aspire to making education available for all children, a recent review paper prepared for the World Education Forum held in Senegal in April 2000, estimated that 113 million children have no access to primary education; particularly disadvantaged were girls, working children and those with special needs. In affluent countries, children with intellectual disabilities have traditionally attended special schools where they were available but increasingly parents are opting for regular schooling with extra supports. In the developing world, few special schools exist and for most countries this is an unaffordable option even if it was thought desirable. Hence the only opportunity for many children with intellectual disabilities is to be educated is by attending their local school (Hegarty, 1993). For these families, inclusive education is not an option but a necessity.

Yet given class sizes and the lack of expertise among teachers, it is vital that families continue to support the child's learning. This may mean maintaining close contact with teachers, finding people who can assist in classes - such as retired teachers or older siblings - and assisting with home-work.

If possible teenagers and adults should also avail of further education opportunities, such as vocational training courses provided locally.

## **Productive Employment**

Disability and poverty are often first cousins throughout the world but more especially in poorer countries where there are no social security benefits. Any member of the family who is not productive is then a drain on family resources. Hence as far as possible, children with intellectual disabilities need to become self-reliant in their personal care and be able to undertake jobs around the house such as water fetching so that the family workload is shared.

It's better still if the young people can play a part in income generation perhaps by assisting on the family farm or business or by holding down a job with local employers (Neufeldt, 1995). The latter option is becoming more of a reality in developed countries with the advent of supported employment schemes in which a support worker trains the person with a disability on the job and remains available to offer support and guidance to employers and co-workers should problems arise. It is

possible that similar schemes could operate in developing countries; especially in urban areas and as industrialisation advances.

If people have a source of income the options for their care outside of the family are also increased.

### **Staff training**

In all communities of the world, there are two groups of people who can be of particular help to families with disabled children; namely primary healthcare workers (Berman et al, 1987) and teachers in nursery and primary schools. Both groups often lack experience and training in dealing with children with intellectual disabilities. A priority is to ensure that knowledge and skills related to disabilities are made available to them through their initial training courses or as part of their in-service training.

The Community Based Rehabilitation Programme in Guyana, South America has produced a number of training packages based around specially made video-programmes recorded in family and community settings. These programmes are shown in villages with a locally recruited person to act as course leader (O'Toole and McConkey, 1998). Experienced community volunteers (including parents of people with disabilities) have organised local courses for various groups using specific training packages. For example, a training package on integrating children into mainstream schools has been used by a cadre of experienced CBR workers to provide a 20 hour training course for teachers from nursery and primary schools in their areas. Nearly 300 teachers participated in local courses in one year. Likewise a training package giving basic health messages - Facts for Life - was presented by local CBR teams to over 4,000 persons in the interior region of Guyana and two recently produced packages aimed at promoting the well-being and development of all children and hence preventing developmental disabilities have been used with approximately 2,000 persons.

When we free our mind from the traditional image of 'trainers in disability' services; then we can begin to appreciate that the number of potential tutors could be very much greater if they were provided with suitable resource materials. Community staff; parents of people with disabilities; people with disabilities themselves – are but three groups who would be well motivated to undertake the

task. Their skills and confidence for this task can be developed through training workshops (McConkey et al, 2000).

## **Conclusions**

Intellectual disability affects every nation and many thousands of families around the world. Despite the best efforts of medical science and disability specialists, the incidence of this disability is set to rise internationally over the coming decades (Helander, 1993). Hence the need for effective supports for families will continue to be present despite the demographic and societal shifts present in affluent countries and which already are impacting on developing countries; the drift to the cities, retraction of the extended family and breakdown of localised communities to name but three.

Yet the past decades has brought greater hope to families who give birth to a child with an intellectual disability than in any previous generation. The vision of an ordinary life-style is coming closer to reality as these young people attend schools, obtain paid work and gain their own homes. Moreover there is greater acceptance internationally of human rights and equality of opportunity.

These gains did not come by chance or as the side-effect of other efforts. Rather they were hard-won through the efforts of parents, professionals and people with disabilities. Their legacy is not just the tangible services they have helped to create but also the systems and processes that produced these outcomes; most notably the family associations that now exist in nearly all countries. To let these initiatives wither through apathy or ignorance is to put at risk a better life for those world citizens as yet unborn, who will bear the label 'intellectually disabled'.

## **References**

Barenok, T. and Wieck, C. (1998) Partners in Policy-making: Far more than the object of policy. In L. Ward (ed.) *Innovations on Advocacy and Empowerment for People with Intellectual Disabilities*. Chorley: Lisieux Hall Publications.

Bersani, H. (1998) From social clubs to social movement: Landmarks in the development of the international self-advocacy movement. In L. Ward (ed.) *Innovations on Advocacy and Empowerment for People with Intellectual Disabilities*. Chorley: Lisieux Hall Publications

Bornstein, M.H. (1991) *Cultural approaches to parenting*. New Jersey: Lawrence Erlbaum Associates.

Brohier, B. (1995) Funding services. In B. O'Toole and R. McConkey (eds.) *Innovations in Developing Countries for People with Disabilities*. Chorley: Lisieux Hall Publications.

Carpenter, B. (1997) *Families in context: Emerging trends in family support and early intervention*. London: David Fulton Publishers.

Chen, J. and Simeonsson, R.J. (1994) Child disability and family needs in the People's Republic of China. *International Journal of Rehabilitation Research*, 17, 25-38.

Farran, D.C. (1990) Effects of intervention with disadvantaged and disabled children: A decade review. In S.J. Meisels and J.P. Shonkoff (eds.) *Handbook of early childhood intervention*, Cambridge, Cambridge University Press.

Gartner, A., Lipsky, D.K. & Turnbull, A. (1991) *Supporting families with a child with a disability: An international outlook*. Baltimore: Paul Brookes Publishing

Helander, E. (1993) *Prejudice and Dignity: An introduction to Community-based Rehabilitation*. New York: UNDP.

Hegarty (1993) Education of children with disabilities. In P. Mittler, R. Brouillette and D. Harris (eds.) *World Yearbook of Education 1993: Special Needs Education*, London: Kogan Page.

Herbert, E. and Carpenter, B. (1994) Fathers – the secondary partners: professional perceptions and a father's reflection. *Children and Society*, 8, 31-41.

Ingstad, B. (1988) Coping behaviour of disabled persons and their families: cross-cultural perspectives from Norway and Botswana. *International Journal of Rehabilitation Research*, 11, 351-360.

Krauss, M.W., Seltzer, M.M., Gorden, R. and Friedman, D.H. (1996) Binding ties: The roles of adult siblings of persons with mental retardation. *Mental Retardation*, 34, 75-82.

Kwok, J. (1995) The role of the family in disability concerned politics and services: challenges for community based rehabilitation in the Asian and Pacific decade of disabled persons, 1993-2003. *International Journal of Rehabilitation Research*, 18, 351-356.

McConkey, R., Mariga, L., Braadland, N. and Mphole, P. (2000) Parents as trainers about disability in low income countries. *International Journal of Disability, Development and Education*, 47, 309-317

McConkey, R. and Mphole, P. (2000) Training needs in developing countries: Experiences from Lesotho. *International Journal of Rehabilitation Research* (in press).

Mittler, H. (1994) International initiatives in support of families with a member with a learning disability. In P. Mittler and H. Mittler (eds.) *Innovations in Family Support for People with Learning Disabilities*. Chorley: Lisieux Hall Publications.

Neufeldt, A. (1995) Self-directed employment and economic independence in low-income countries. In B. O'Toole, B. and R. McConkey (eds.) *Innovations in Developing Countries for People with Disabilities*. Chorley, Lancs.: Lisieux Hall Publications.

O'Toole, B. (1995) Mobilising Communities in Guyana. In B. O'Toole and R. McConkey (eds.) *Innovations in Developing Countries for People with Disabilities*. Chorley: Lisieux Hall Publications.

O'Toole, B. & McConkey, R. (1998) A national training strategy for personnel working in developing countries: An example from Guyana. *International Journal of Rehabilitation Research*, 21, 311-321.

Rubin, I.L. and Davis, M. (1986) Etiology of developmental disabilities in Soweto, South Africa. *American Journal of Public Health*, 76, 1112-1114.

Russell, P. S.S., John, J.K. and Lakshmanan, J.L. (1999) Family intervention for intellectually disabled children. *British Journal of Psychiatry*, 174, 254-258.

Skogmo, P. (1995) Fostering the formation of parents' associations. In B. O'Toole and R. McConkey (eds.) *Innovations in Developing Countries for People with Disabilities*. Chorley: Lisieux Hall Publications.

Tse, J.W.L. (1995) Community-based social services for people with learning disabilities in the People's Republic of China. *British Journal of Learning Disabilities*, 23, 28-32.

UNICEF (1989) *Facts for Life: A Communication Challenge*. Geneva: United Nations.

UNICEF (2000) *The State of the World's Children*. Geneva: United Nations

World Health Organisation (1985) *Mental Retardation: Meeting the Challenge*. Geneva: WHO.

Zinkin, P. and McConachie, H. (1995) *Disabled children and developing countries*. London: Mackeith Press.