Good practice for people working with children

CHILDREN AT RISK GUIDELINES

TEARFUND
CHRISTIAN ACTION WITH THE WORLD'S POOR

Children with Disabilities

CHILDREN AT RISK GUIDELINES: VOLUME 3

AUTHORS Glenn Miles – Child Development Consultant
Paul Stephenson – Child Development Advisor, Tearfund

EDITOR Fiona Anderson – Freelance writer

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Preface

What are the principles of good practice in the area of Child Development and how can we implement them? This series sets out the basic principles of Tearfund's Child Development Policy, and then seeks to apply them in different contexts. Here in Volume 3 we look at children with disabilities. We recommend that you use this framework in conjunction with the *Tearfund Child Development Study Pack* (for details of how to order the study pack and other volumes see page 86). The study emerges from comprehensive field research and dialogue and has been reviewed by a variety of experts and practitioners. The authors hope and pray that you will find it useful and practical, and that for all who are working with children it will help you in changing children's lives for the better.

Glenn Miles and Paul Stephenson

November 2001

A note about the authors

GLENN MILES is a paediatric nurse who has been involved in setting up an information resource centre for parents of children with special needs and professionals working with the same in London. He has also had extensive child development experience in Asia including being involved in setting up a community disability programme in Cambodia.

PAUL STEPHENSON currently works as Tearfund's Child Development Adviser. He has seven years experience of development and relief in Latin America, Africa, Asia and Eastern Europe, and has a background in education, community development and programme evaluation.

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NOTE The terms **First** and **Third Worlds**, **developed** and **developing countries** have been used interchangeably throughout the text as commonly accepted terminology for industrialised and developing countries.

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CHRISTIAN ACTION WITH THE WORLD'S POOR

SECTION 1

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1 Introduction

WHAT IS DISABILITY?

When I first wrote this paper I kept referring to 'disabled children'. I was rightly criticised because children with disabilities are first and foremost 'children', and only then 'with disabilities'. This is more than semantics. It is a reminder of what our priorities should be when working with children with disabilities. Labelling can be one of the biggest disadvantages they face.

Tearfund believes that we must focus more on what children *can* do than on what they cannot do. International Classification of Impairments and Handicaps by the World Health Organisation (WHO) refers to the concept of *disablement*. (See FIGURE 1) This moves away from the strict medical model. The more positive concepts of *activities* and *participation* replace the terms *disability* and *handicap*. However, we must remember that 'words can be politically correct and well packaged, but the majority of people with disabilities are lonely, lost, isolated and often ostracised by society.'[1] A change of words is not enough unless it signals a genuine change in attitudes.

FIG 1
WHO INTERNATIONAL CLASSIFICATION OF IMPAIRMENTS AND HANDICAPS

Impairment	A loss or abnormality of a body part (ie structure) or body function (ie physiological function). The physiological functions include mental functions.
Activity	Everything a person does from simple activities (eg grasping, moving a leg, seeing) to complex skills and behaviour (eg remembering past events or acquiring knowledge).
Activity limitation (formerly disability)	Difficulty in the performance, accomplishment or completion of an activity at the level of the person because of eg pain/discomfort, doing it too slowly/quickly or not at the right time/place
Participation	Participation comprises all areas or aspects of human life, including full experience of being involved in practice, custom, or social behaviour.
Participation restriction	The disadvantage for a person with impairment that is created or worsened by environmental and personal factors.

Source: WHO ICIDH – 2 (1997)

1 Nigel Poulton (Case study – Village Disability Programme).

The medical model of disability adhered to by many doctors has viewed impairment as an 'abnormality' which needs to be 'corrected', 'cured' or 'overcome'. It is based on the concept that the human body is alterable and that the social environment is unalterable. The social model of disability developed by community-based practitioners stresses that a handicap or disability is a relationship between an individual and his/her environment and shows an increased acknowledgement of the role societies play in disabling a person.[2]

This paper does not look at the emotional and social disability caused by sexual abuse and exploitation, which is looked at in *Children at Risk Guidelines 4: Children and Sexual Exploitation and Abuse*.

HOW MANY CHILDREN HAVE DISABILITIES?

One in twenty children are born with a disability or become disabled during their childhood. FIGURE 2 gives UN estimates of the incidence of different kinds of disability.

FIG 2
UNITED NATIONS DESCRIPTION OF PREVALENCE OF DISABILITY

TYPE OF LIMITATION	PREVALENCE
Moving difficulty	2.0–2.5%
Seeing difficulty	0.5–0.8%
Hearing/speech difficulty	0.5–0.8%
Learning difficulty	0.2–0.4%
Chronic fits	0.3–0.6%
Strange behaviour	0.1–0.2%
Feeling difficulty (in hands or feet)	0.1–0.2%
Combinations of the above	0.2–0.3%
TOTAL	**4–5% approx**

Source: Helander, E (1993) *Prejudice & Dignity* UNDP

It is generally the poorest children who are most likely to be disabled.

It is generally the poorest children who are most likely to be disabled. This may be due to comparatively poor maternity care during pregnancy and delivery. Other factors are the unsafe environments in which the poor often live, and the lack of available care and support which compound their disabilities.

Children in developing countries are especially vulnerable. They may be forced through poverty into dangerous occupations, for example on building sites, or in mines or factories, where safety precautions are inadequate. Campaigning for safe

2 Hartley and Wirz (1993).

Children with disabilities in developing countries experience some of the deepest discrimination of all children.

working conditions and against all forms of 'exploitative' labour is therefore crucial for working children. Street children working at road junctions washing cars or selling cigarettes to people in cars are at great risk of road traffic accidents. If they are injured they are less likely to get any treatment, care or support, and more likely to develop complications. Even where rehabilitation is available, they may not have access to it.

War and conflict increase children's vulnerability to injury and permanent disability, especially from land-mines and other unexploded ordinance. This is made worse by the mental trauma and stress suffered as a result of personal injury or loss of, or separation from, family members.

Whatever the cause, children with disabilities in developing countries experience some of the deepest discrimination of all children throughout the world.

WHAT DOES THE BIBLE SAY ABOUT DISABILITY?

'Those parts of the body that seem to be weaker are indispensable, and the parts that we think are less honourable we treat with special honour… Now you are the body of Christ and each of you is a part of it' (1 Corinthians 12:22-3, 27).

We need to accept that none of us is fully whole.

Each and every child is a unique individual, created in the image of God and with inherent worth (Genesis 1:26). But each one of us is flawed. If full maturity is seen as 'attaining to the whole measure of the fulness of Christ' (Ephesians 4:13) in whom 'all the fullness of the Deity lives in bodily form' (Colosians 2:9) we need to accept that none of us is fully whole. As Christians, we believe this to be true whether or not a child has a physical or mental disability. In fact, we will only reach complete wholeness in heaven. Even Jesus himself had to live out his life in human form with all the limitations that human bodies impose.

Nevertheless, there is a sense in which 'the concept of wholeness is very much a part of accepting/understanding that disability is simply a small part of who a person is'.[3] Children with disabilities are 'whole' as they are and to say otherwise perpetuates the negative stereotypes: 'It also perpetuates the notion that a disabled body means one is not a whole person – thinking, sexual, and with the same needs and desires as non-disabled.'[4] We need to encourage children with or without a disability to reach the full degree of their God given potential.[5]

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3 Nancy Lane.

4 Ibid.

5 Sidebotham (1998).

ENABLING CHILDREN TO REACH THEIR FULL POTENTIAL

All of us need to experience God's love. Unfortunately, children with disabilities more than other children may experience prejudice and rejection from an early age. The response of the church must be to provide an alternative loving environment. It can be painful to be different, but in God's 'upside-down' Kingdom, 'to shame what is strong, God has chosen what the world counts weakness' (1 Corinthians 1:25-31). Jesus invites his disciples to touch the holes in his body. In so doing he can be seen to be 'challenging the way non-disabled people avoid those with disabilities'.[6]

Children with disabilities should not be seen as existing only to enable others to serve God better

Some key Biblical characters, like Moses (Exodus 4) and Paul (2 Corinthians 12: 9), had impairments. It has been suggested that this surely 'wouldn't have been the case if God didn't mean impaired people to be around'.[7] Both Moses and Paul were specifically chosen for their tasks of spreading God's message and yet in Exodus 4:11 God said to Moses about his speech impediment: 'I made you thus'. Paul's body metaphor (1 Corinthians 12) suggests that all people, including children with disabilities, are created to reveal the general inter-dependence of human beings, rather than either dependence or supposed independence. Children with disabilities should not be seen as existing only to enable others to serve God better. This could give the message that the server is more important than the recipient.

In many belief systems and cultural contexts disabled children are seen as a liability. They are not a priority for families or communities or even for health and public services. In the New Testament it was different. The church was continually encouraged to reach out to those with whom we wouldn't normally feel comfortable and to love them unconditionally – in the story of the the good Samaritan, for example. But as Jean Vannier, founder of the L'Arche communities where people with disabilities and others live together in community, has observed: 'Loving someone is not doing things for them but revealing to them that they are precious.' Disability is not due to the sin of the child or parents. Nor is it because of their lack of faith. It may be a wonderful revelation to a child with disabilities when they find that God loves them unconditionally, and that they have the same access to him in prayer and worship as any other child, man or woman. 'I call you by name', says the Lord. 'You are mine' (Isaiah 43:1).[8]

6 Taylor and McCloughry (1998).

7 Mel Horne of Church Action in Disability.

8 Bowers (1996).

WHAT IS THE BEST WAY TO WORK WITH CHILDREN WITH DISABILITIES?

Historically, children with disabilities, especially those who were described as 'mentally retarded', were kept out of sight in huge asylums. For example, London is surrounded at a distance by a ring of asylum hospitals. Alternatively, children were put into special schools such as a school for the blind. This pattern was exported to much of the developing world – so much so that governments and Christian organisations have until recently seen institutions as the main way of dealing with the 'problem' of disability.

However, things have gradually been changing. United Nations Development Programme research[9] outlines four key components of programmes working with people with disabilities in third world countries:

- Mobilising the family and community.
- Empowering people with disabilities themselves.
- Changing attitudes of people towards disability.
- Improving knowledge and increasing access to information.

All of these aspects are considered in this document, and reflect a community-based rehabilitation[10] (CBR) approach.

Community Based Rehabilitation

CBR has numerous advantages. It tends to reach a larger population than an institution. It is more likely to be aware of family needs, opinions and circumstances. It relies on appropriate low cost technology and it aims to prevent people with disabilities being isolated from their community.

Some community child health programmes (see *Children at Risk Guidelines 2: Children and Community Health*) will include screening for children with disabilities. Outside the family and immediate community it is often the community health worker (CHW) or traditional birth attendant (TBA) who is one of the first persons to see a child born or left with a disability following illness or accident. Their initial response to a child's disability is vital to the way families and the child will respond to further help. Therefore they must be aware of the issues; know the best ways to support the family and when, how and where to refer people.

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9 Helander (1993).

10 Sometimes CBR is used to describe programmes at national and provincial level, while local level interventions are known as village based rehabilitation (VBR). However, in this framework, CBR is used with reference to programme interventions at all levels which incorporate the principles outlined above.

The CHW may also be able to help prevent some types of disability, depending on their level of training and experience. For example, a good immunisation programme can prevent polio. The more traditional community-based rehabilitation workers support the children and their families to make the most of their own resources and those of the community.

However, it is also recognised that some children will be so severely disabled that their families will be unwilling or feel unable to have their children with them. In some cases, parents may resort to infanticide at, or shortly after birth. Even where this does not happen the child may well die from malnutrition, malaria or chest infection in the first year. However, if they do not die, then they are likely to survive for some time which requires a long term commitment.

Good community based rehabilitation (CBR) can enable many families to keep the child with them.

Good community-based rehabilitation (CBR) can enable many families to keep the child with them. If they are supported in every way possible to work with the child, they can experience the benefits and joys of raising a child with disabilities, as well as the heartaches and stresses. Whether children are able to stay at home or not, however, will often depend on whether there is an older sibling, grandparent or other adult to take responsibility for them. The main care givers are usually immediate family and their ability to work with the child with disabilities will depend on their work, chores, or schooling needs, for example. It also depends on the extent of the impairment.

THE MAIN CARE GIVERS ARE USUALLY THE IMMEDIATE FAMILY

Institutionalisation or residential care

If the family feel unable to cope, they may seek to put the child in an institution, even where community rehabilitation is available. Residential care for some may be unfortunate but inevitable. It should not be the *only* option available, but it may need to be *one* of the options, though selection criteria for admission must be strictly adhered to (see *Children at Risk Guidelines 5: Children in Residential Care and Alternatives*).

In some cases the government may provide residential homes for children with disabilities, but often these are inadequately staffed and so physical and emotional care is poor. Children may be fed on their backs, washed with a hose, tied to the bed etc but even more disturbing they may receive no opportunity to feel a caring touch. Programmes seeking to work in these situations will need to be committed for the long term. They will need to be diplomatic when dealing with managers and staff and to seek alternatives such as day centres where some children can be cared for well during week days. It may be better to work well with a few children than work poorly with a large number.

Christian organisations may have set up and run residential institutions for a number of years. They too will need to re-evaluate their programmes to see if they can be involved in prevention, advocacy, and the development of alternative forms of care.

It may be helpful to look at *Children at Risk Guidelines 5: Children in Residential Care and Alternatives* for programmes that are working with children with disabilities in residential as well as community-based programmes. Where at all possible Tearfund prefers to support programmes which are community rather than institution based.

Advocacy

Another way in which the issue of disability can be approached is through advocacy, where the attitudes of the public, health, education and social service/voluntary sector professionals and especially parents can be influenced to see beyond the disability to the ability of the child.

As a result of raised awareness and advocacy initiatives over the years, mainstream schools have become more proactive in integrating children with disabilities. This helps children not to feel so different and avoids the problems of institutionalisation. It also breaks down prejudice as children see those with disabilities participate in learning and leisure activities. Integration requires the training of teachers, although teachers themselves have often been the ones seeking help to make integration work.

Challenging traditional attitudes is often a vital step in improving the lives of children with disabilities.

In conclusion, a community-based rehabilitation approach, where children, their families and communities are all involved, is usually considered to be the best way to work with children with disabilities. Residential care may be necessary as a last resort, but the emphasis should be on seeking and developing alternatives where possible. Underpinning both these approaches, advocacy has an important role in tackling prejudice. Challenging traditional attitudes is often a vital step in improving the lives of children with disabilities.

INTEGRATION BREAKS DOWN PREJUDICE AND AVOIDS INSTITUTIONALISATION.

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SECTION 2

Framework for Good Practice

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2 *Framework for Good Practice*

This section expands Tearfund's general Child Development policy and seeks to apply it specifically to projects working with children with disabilities.

PRINCIPLE 1 BUILDING RELATIONSHIPS

1.1 Priority is given to building relationships – with the child, family, community, organisation or institution and between agencies.

- Often parents of children with disabilities and the children themselves can feel isolated, both physically and emotionally. Developing a relationship with them is the key before other forms of support can even be considered.

PRINCIPLE 2 PARENTAL RESPONSIBILITIES

2.1 Parental responsibilities towards children are encouraged, as is the development of a caring, child-friendly community.

- It is essential that the professional therapist, social worker or the primary trained community rehabilitation worker does not see their role as replacing the parent but complementing it.

PRINCIPLE 3 WORKING AT DIFFERENT LEVELS

3.1 There is an awareness of what level the programme is addressing, whilst consideration is also given to other levels:

- Individual
- Peer
- Family
- Organisational/Institutional
- Community
- National
- Policy/Political
- Spiritual

PRINCIPLE 4 IDENTIFYING NEEDS AND PRIORITIES

4.1 Children's (and parent's) needs are identified. This includes listening to and involving children and parents.

Rehabilitation

- A programme's focus on one area, such as physical or mental impairment, should not be to the exclusion of other needs. Disability focused programmes are at risk of 'forgetting' wider spiritual, emotional or social issues, for example.
- Programmes must have the child-centred goal of compensating for the loss of the child's sensory, cognitive and motor facilities as well as optimising the ability of the child to perform a range of activities within their home and community environments.
- An assessment of what the child is able to do (function) rather than of their medical diagnosis means that children can be cared for in a way which is more relevant to the child and their families' day to day problems. It is also cheaper than expensive medical care.
- Where possible, low cost appropriate technology and local expertise should be used in the design of toys and items of equipment that help with mobility and function. Individual assessment of the child will ensure that the correct equipment is made and used.
- Assessment must take into consideration each family's own perceived needs. Such an assessment is time specific and will change over time. Each family member has their own needs as well as the family as a whole. A family's strengths as well as needs should be ascertained. This should be reviewed on a regular basis, perhaps once or twice a year. Care must be taken not to raise unrealistic expectations.
- Families should have the opportunity to share in the care of the child with disabilities. It should not be assumed that it is entirely the mother's responsibility.
- Families should be able to decide themselves the level of involvement they feel able to commit to programmes. Where possible, programmes should enable families to identify their own needs and develop their own solutions. They need to participate in those solutions themselves rather than looking to professionals to do it for them.
- Children with disabilities have the same basic needs as other children; clean water, food, clothing, shelter, protection and consistent loving care. Intervention can threaten the attainment of the basic needs by placing excessive demands on family

time and resources. In some poor communities, especially in times of crisis, poverty, overwork, severe social tension and exhaustion may make parental involvement difficult and, exceptionally, unrealistic. This must be taken into consideration when anticipating parental involvement.

- Children with disabilities are at higher risk of being sexually abused due to their increased vulnerability. Care must be taken in the selection of staff involved in the care of children. Parents and family members are sometimes the abusers of children so vulnerability and strategies to prevent abuse should be discussed with parents.

Prevention

- The importance of appropriate levels of screening for handicap and disability must not be underestimated, especially in programmes where in order to save money, screening services have been stopped by government. Early recognition can prevent additional disabilities. All too often behavioural problems arise as result of frustration from handicap; the anti-social behaviour is too often attributed to self will rather than being recognised as an indicator of an underlying problem.[11]
- Schools can be encouraged to train teachers to identify deafness, partial sight, malnutrition, learning difficulties, language development and motor skills using basic tests. Schools can also be involved in prevention by using and adapting 'Child to Child' Activity sheets with the children (see Resources). This will of course depend on the openness of the school to learning and the commitment of the education authority to input from external agencies.
- Where a cause is identified appropriate action can be taken.

Examples of cause and response

- Vitamin A deficiency can cause corneal opacities, retinal problems and cataracts which can all lead to blindness, so Vitamin A supplementation could be used and promoted.
- Hypothyroidism/Cretinism can be caused by insufficient iodine in the diet so iodised salt/oil capsules can be used where affordable/available and advocated where not.
- Malnutrition can result in poor muscle growth and learning difficulties.
- Chronic infection (hookworm, schistosomiasis) can cause anaemia so treating these infections can help limit the effects.

All of these interventions can have a significant impact on preventing long term disability.

11 Tomkins (1998).

- Polio can be successfully eradicated by vaccines. Immunisations can be promoted and used to prevent disability from polio. Immunising girls aged 12–14 years against rubella can prevent her future babies from becoming blind. Children should also be immunised against measles and mumps (MMR) and diphtheria, whooping cough and tetanus (DPT) as indicated by national guidelines.
- Poor traffic safety of motorists and pedestrians leads to road traffic accidents and thousands of injuries to children every year. Initiatives to enforce legal requirements for motorists and teaching school children road safety can help to prevent accidents from occurring.
- Safety in the home and public spaces can be promoted in schools and local women's groups especially with information on the dangers and prevention of burns of young children and falls.
- Areas where there is poor midwifery care may also have a high incidence of children with mental disability because of delay in the baby passing through the birth canal leading to poor oxygenation of the brain. This can also lead to cerebral palsy. Good antenatal care is vital. Sexually transmitted diseases should also be treated.
- Pregnant women may also need education about the use of iron and folic acid supplements and the misuse of drugs and alcohol during pregnancy.
- After delivery, women should be actively encouraged to breastfeed which supports an infant's physical and mental development.
- Identification of genetic predisposition to disability is only available to the wealthy in the developed world so is not relevant here. However, it may be appropriate in certain tribal areas to be aware of the frequency and risks associated with first cousin marriages.
- Preventive measures could be prioritised according to the prevalence of disabilities in a particular area. This will need to be decided by the community rather than the professionals.

4.2 Staff are experienced and trained in communicating with children and their families and helping facilitate children's participation.

The aim is to support and be accountable to the child/family and facilitate *children's participation*. Physical and psychological communication barriers need to be taken into consideration.

- Staffing levels and training needs should be regularly reviewed and all staff working with children should have training in how to communicate with children and their families.
- Special effort should be made to ensure that staff are aware of prejudices towards children with disabilities, including those which are unintentional/cultural.
- Staff need careful orientation to understand that they are not simply caretakers of children. They may be the first group to understand and appreciate the children's potential and can communicate their enthusiasm to parents, families and communities and other carers such as government institutional carers.
- Derogatory words for people with disabilities such as 'spastic', 'cripple', 'sub-normal', should be avoided at all times. Staff should be challenged to use positive terminology to replace negative. Children should be talked to/about using their name.

The frequency and type of communication with a child with disability will depend on:

- the expectation of the carer as to the understanding and potential response of the child.
- whether the child is regularly spoken to and therefore is used to responding.

The carer should therefore *expect* that the child understands them, and should talk to them so that they are not further 'disabled' by low expectations when communication is possible. This will involve an understanding of the importance of touch, of eye contact and speaking kindly to the child even if they appear not to understand anything.

- Anyone working with a child should seek and involve the carer who is most able to communicate with the child and speak for them.
- Children with *speech impairments* and deafness and their families will need special attention to communication needs.
- Children with *visual impairment* should get plenty of touch and speech contact and care should be taken not to over-protect them which might not allow them to become more independent.

Different types of children with disabilities and not only those who are deaf may have communication problems of some kind. A study by Hartley, S (1995) found that 49% of those surveyed in Uganda indicated there was a communication 'difficulty'.[12]

12 See Wirz and Winyard (1993).

- Every effort should be made to ensure that the staff pose no threat to the children either through physical or sexual abuse. Preventive, detection and support strategies should be considered and staff need to be aware of the consequences.[13]

4.3 There is awareness of the spiritual, physical, mental, emotional and social (including educational and vocational) aspects of the child's development.

- Programmes working with children with disabilities can tend to focus on the impairment rather than seeing the child as a whole person with spiritual, physical, mental, emotional and social needs.
- Children with disabilities do develop even though their development may be slower and may not reach the same educational level as other children.
- Children with disabilities need support and stimulation as much as any child. They need play and education and the opportunity to play with other children. Where possible children who are not disabled should have the opportunity to play with those who are so that prejudices can break down. This might be encouraged within families by siblings being carried on hips or in slings rather than kept in the house. This then sends a positive message to others in the community.
- Children with learning disabilities can develop a faith in God. Churches must be made welcoming and accessible to the children. This will involve adequate physical access, transport to and from church, and the use of appropriate communication strategies. For example, those with learning disabilities may need to hear a simple but not patronising message that they can understand. Deaf children may also need interpretation of the message using signing. Children may enjoy participating by playing musical instruments, singing in choirs and in sporting activities.

PRINCIPLE 5 CHILDREN'S PARTICIPATION

5.1 Children's abilities and needs are taken into consideration, with an emphasis on their abilities rather than disabilities; their resilience to change and trauma, rather than simply their vulnerability.

- There should be no prejudice based on gender, age, parentage, ethnicity, social class/caste, religious background or type of disability.
- Children with disabilities are more vulnerable to abuse than non-disabled children. Not only may they be subject to direct forms of physical, sexual and verbal assault,

13 Berglund (1997).

14 Priestly (1998).

A working children's union in India debated the composition of the children's representative body at village level. The key issues were caste, gender and age. However, one of the children they knew was mentally disabled. Despite her limitations, they felt that she had as much right as any of them to be involved in decision making and participation in the Union. She became included in the Union meetings and could vote on equal terms. This had a positive impact on her self-esteem and sense of belonging. The Union enshrined the principle of equal participation for all children, irrespective of disability, within their statutes.

they are also subject to specific forms of neglect and abuse including: lack of stimulation, overprotection by carers, physical segregation, social isolation, poor access to services, physical restraint, forced feeding and different forms of denial of choices. They are also likely to be born, grow up and live their lives in poverty.[14] Much of this is due to prejudice rather than lack of potential.

- Children with physical disabilities are generally as capable of participating in decision-making as non-disabled children of the same age.
- For children with learning difficulties, their ability to participate will depend on their understanding but they should be given the opportunity and encouraged to contribute as much as possible.
- Labelling of children as 'disabled' can be dis-empowering in itself. Stereotyping of families with children with disabilities into a 'handicapped family' should also be avoided.

5.2 Adults collaborate with children, according to their age and ability, individually and collectively, in things that affect them.

- The level at which children are able to participate will depend on their cognitive understanding and age. As much as possible, children should be given a choice about things that affect them personally such as what clothes they would like to wear, what vegetables they would like to eat, what toy they would like to play with. As children get older they should be given more responsibility according to their age and ability within the cultural norms of non-disabled children.
- Creative ways of involving children in how the programme runs should be sought. The assumption should usually be that they can and should be involved. This can be done individually and in groups so that children can learn from each other.

PRINCIPLE 6 CHILDREN IN CONTEXT

6.1 Children are considered in the social, political and historical context of their community.

- Children, including those with disabilities, should be valued and active members of their family and their society. The programme should seek to put children in the context of their community and not remove them from it. Centres set up for children with disabilities should not be seen as separate from the community but part of it.

6.2 Parents, caregivers and families are involved and impacted.

- Where it is known, and where staff are capable of making an accurate diagnosis, parents and children must be informed. Information enables families to make informed decisions in collaboration with the child and reduces professional paternalism.
- Families are not 'disabled' except by societies' (including professionals') labels. Society and its reactions towards families can create dysfunctionality in families. Programmes must seek to address this by educating professionals and where possible the public, especially the church (see Advocacy).
- Family involvement may be difficult due to practical factors (eg lack of money, time, energy, support) and attitudinal factors (eg overprotection or neglect). The programme should help family members to adapt to their practical, social and spiritual circumstances (including the child's disability) and promote an optimal home environment for the child's development.

In more developed countries independence is a characteristic to which adolescents (including those with disabilities), aspire. In less developed countries, however, there is more emphasis on interdependence. The emphasis is on the extended rather than the nuclear family, on cooperation rather than competition, and on the present rather than on the future. These differences may also be evident between the educated city trained professionals and the rural or slum poor.

6.3 The child's community is involved and positively impacted.

- Prejudices and stereotypes of disability held by family, village head, committees should be challenged.
- Communities must be informed and educated about the ability rather than inability of children with disabilities to minimise prejudice and encourage potential. Opportunities for able-bodied children to interact with children with disabilities can help this process.

- It is important to understand the culture of the community in order to develop an appropriate programme response.

6.4 Links (networks) are developed with other local, national and international organisations, including those from other sectors.

- It is especially important that collaboration is sought with schools so that children able to benefit from schooling can do so. This may involve training of teachers; provision of materials and equipment together with and training in its correct use and adaptation.[15]
- Regular meetings with other disability rights organisations and community development organisations are also important.

6.5 The cultural and religious context of the child, family and community is taken into consideration.

- Fatalistic beliefs and negative superstitions concerning specific disabilities can be questioned where good relationships have been established. The stigma of disability is very frequently attached to the parents as well as to the child.
- Some pastors attempt to encourage families of children with disabilities, saying that God has demonstrated trust in them as parents by giving them the responsibility of caring for such a precious but vulnerable child. However, families can be seriously damaged by this kind of thinking: 'Parents internalise this as guilt, and believe that God is cruel, the church is abandoning them and placing the burden on the family rather than the church community. Parents go through so much grief, loss and stress, they do not need this added burden.'[16]

Beverley Ashton of Action for Disability and Development emphasises how important it is that Christians are informed to counteract the belief that disability is due to sin, or that all children with disabilities only need to experience enough faith for God's healing. The vulnerability of a child whose mobility is restricted must not be abused by people praying over children, leaving them feeling guilty that they have not been healed and have let people down. Carers and pastors may need to protect them from insensitivity. Praying with the child about issues important to them may be much more healing.

15 SCF Videos on Inclusive Education are a good resource here – available from SCF HQ.

16 Nancy Lane, Disability Awareness and A Healing Ministry (see Resource list).

- It may be appropriate to put families of children with similar disability in touch with each other. This may also be possible through vocational training. Families appreciate and even prefer the emotional support of other families with children who have the same disabilities.
- Vocational training can provide ability and competence in practical skills that are income generating. Certain types of work are traditionally associated with disabilities, such as music for the blind, for example. But opportunities can be much more varied, and this sort of labelling should be avoided.[17]

PRINCIPLE 7 **ADVOCACY**

7.1 Lobbying and interceding with or on behalf of children and their families takes place at local, national or international levels.

- Families, together with programme and national networks, can be involved in advocacy initiatives. Linking with other groups will obviously help small programmes address the bigger issues.
- Changing the attitudes and practices which marginalise people with disabilities in society is essential. People should be encouraged to reflect upon the situation of people with disabilities and understand the deeper causes of impairment and disability. This is true as much for professionals and others working with children as for the general public.
- Training is key for anyone coming professionally into contact with people who are disabled, including health, social, and educational professionals and religious leaders.
- Importance is placed on lobbying alongside people with disabilities for rights and access to employment.
- Vocational training has intrinsic benefits for the person with disabilities. But there must also be work available after training. For example, it is only appropriate to train people in a skill if there is a need for it. If work is not available, discouragement will be the result.

7.2 The programme staff are aware of the importance of the UN Convention on the Rights of the Child and other human rights conventions such as the UN Standard Rights on the Equalisation of Opportunities for Persons with Disabilities.

- It is recognised that different countries will have different attitudes to 'rights' and some will have no functioning national association or disabled people's organisation.

17 Ingstad and White (1995).

- The key article for disabled children within the Convention on the Rights of the Child is Article 2: non-discrimination. It states that the rights set out in the convention be respected and ensured by States Parties 'without discrimination of any kind, irrespective of the child's or his or her parents' or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability of other status'.
- The complementary Article 23 states 'a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self reliance and facilitate the child's active participation in the community'.
- In fact the UNCRC includes 'children with disabilities' all the way through and not just in Articles 2 and 23. The Committee on the Rights of the Child recognised that the situation for children with disabilities was the worst situation of all children.
- Another important document is the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (1993) (see page 31).

Specific advocacy issues include:

- Promoting better care of children in government homes through policies on staffing levels, restraining children, feeding children, and the ratio of children to carers/teachers/physical therapists to provide minimum stimulation.
- Developing 'rights' and equalisation of opportunities for children with disabilities in schooling and vocational training, jobs, self employment and participation in community affairs. Protection of legal and human rights. Also freedom of information legislation and the adequate resourcing of Disabled Persons Organisations (DPOs).
- Disabled Persons Organisations as advocacy groups and service providers are vital for 'developing the self esteem of people with disabilities and breaking down the attitudinal, institutional and physical barriers in society'.[18] However, they need to be democratic in themselves by attempting to represent all types of disability as well as gender and ethnic grouping.
- Government, shops and businesses should be encouraged to improve access to public buildings.
- Raising awareness of needs, rights and issues through media.
- A developing relationship with Ministries of Health, Education and Social Welfare as well as local district level services to provide/improve access to health, education and social work/respite care facilities for families with children with disabilities.

18 Stubbs (1993).

- Appropriate special needs schools and openness of schools with non-disabled children to receive and integrate children with disabilities.
- A balance between the responsibility of the community towards people with disabilities and the responsibility of government to provide services.
- Screening methods to detect disability early on so that appropriate care can be given preventing worsening caused by inadequate early care.

7.3 The barriers to advocacy are understood and addressed.

- These may include prejudices, oppressive governments and organisational capacity.

7.4 There is dialogue with parents and caregivers so that they can make informed decisions and represent their families.

- Parents and families need to know how to lobby for changes in service systems so that the family can meet the needs of the child.
- It may be appropriate to enable groups of parents to lobby together collectively.
- Services should be for the family and families should not have to fit around the services.
- Programmes should avoid the traditional approach of talking only to parents and not to children.

7.5 There is dialogue with children so that, depending on age and ability, they can make informed decisions and advocate for themselves and their peers.

- Children should be involved in hearing about their diagnosis and decisions about their treatment and care.
- Working with Disabled Persons Organisations and children's rights organisations, children and their families should be made aware of lobbying for their 'rights' where appropriate. These might include equalisation of opportunities for children with disabilities in schooling and vocational training, jobs, self employment and participation in community affairs.
- Children themselves can be invited to raise awareness of their needs, rights and issues through the media.

7.6 There is awareness of the Biblical basis of their ministry and the importance of prayer.

- See Introduction and the *Child Development Study Pack*.

UN STANDARD RULES ON THE EQUALISATION OF OPPORTUNITIES FOR PERSONS WITH DISABILITIES

Rule 1 States should take responsibility to raise awareness in society about persons with disabilities, their rights, their needs, their potential and their contribution.

Rule 2 States should ensure the provision of effective medical care to persons with disabilities.

Rule 3 States should ensure the provision of rehabilitation services to persons with disabilities in order for them to reach and sustain their optimum level of independence and functioning.

Rule 4 States should ensure the development and supply of support services, including devices for persons with disabilities, to assist them to increase their level of independence in their daily living and to exercise their rights.

Rule 5 States should recognise the overall importance of accessibility in the process of the equalisation of opportunities in all spheres of society. States should (a) introduce programmes of action to make the physical environment more accessible (b) undertake measures to provide access to information and communication.

Rule 6 States should recognise the principle of equal primary, secondary and tertiary educational opportunities for children, youth and adults with disabilities, in integrated settings. They should ensure that the education of persons with disabilities is an integral part of the education system.

Rule 7 States should recognise the principle that persons with disabilities must be empowered to exercise their human rights, particularly in the field of employment. In both rural and urban areas, they must have equal opportunities for productive and gainful employment in the labour market.

Rule 8 States are responsible for the provision of social security and income maintenance for persons with disabilities.

Rule 9 States should promote the full participation of persons with disabilities in family life. They should promote their right to personal integrity and ensure that laws do not discriminate against persons with disabilities with respect to sexual relationships, marriage and parenthood.

Rule 10 States will ensure that persons with disabilities are integrated into and can participate in cultural activities on an equal basis.

Rule 11 States will take measures to ensure that persons with disabilities have equal opportunities for recreation and sports.

Rule 12 States will encourage measures for equal participation by persons with disabilities in the religious life of their communities.

Later Rules deal with implementation measures.

The full text is available from the Disabled Persons Unit, Department for Policy Co-ordination and Sustainable Development, UN, New York
or on the Website: www.un.org/ecosocdev/geninfo/dpi1647e.htm (see Resources).

PRINCIPLE 8 CHILD-SENSITIVE INDICATORS

8.1 The impact of work on children and their families is measured both qualitatively and quantitatively.

8.2 Indicators show how the programme has an impact on the lives and environment of children (by age and gender) and their families.

- Activities of daily living can be a useful measurement in assessing change. Whether the person with disability can walk independently, dress, undress, feed him/herself, fetch water, contribute to daily household chores, go to school, travel a certain distance etc. The measurement should be of progress in independence and/or self confidence.
  - How has the child learned to live with the disability?
  - How have they set out and achieved their goals?
  - What has been achieved to reach this point either physically, emotionally or spiritually?
- It would also be useful to have a scale to assess the development in knowledge and support of the parents including skills in caring for the child. This is especially important for children who progress very slowly, if at all, in level of function.
- Children with disabilities are not gender neutral but most research with children is not broken down into gender. Boys' and girls' needs and aspirations are different. Analysis by gender is therefore important.[19]

8.3 Parents, caregivers and children (according to their age and ability) are involved in the evaluation of the child and the care given.

- Parents and other caring relatives can be asked how their lives have changed.
  - What are the family able to do that they were unable to do before their child was involved in the programme?
  - Do they have more free time?
  - Is the primary carer able to go to school/work more than before?
- Has the community's attitude changed? Is there less discrimination?

8.4 The programme reflects on and uses the results of impact assessments.

19 Priestley (1998).

SECTION 3

Case Studies

Contents

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3 Case Studies

These case studies cover a wide range of programmes working with children with disabilities. Most were written by programme staff and therefore come from a field perspective. This adds to the authenticity. The programmes are not considered 'ideal' but each has examples of good practice that contribute to the learning process.

Each case study focuses on two or three of the principles outlined in SECTION 2. The *questions to reflect on* at the end of each study give an opportunity to consider your own programme.

Community Based Rehabilitation (CBR) and Day Care Programme, Christian Care Foundation, Nakhonpathom Province and Bangkok, Thailand
A developing programme addressing the needs of children with disabilities in rural areas. It has a day centre for children in an urban area, and also campaigns for re-unification of traced families and fostering/adoption.

Community Based Rehabilitation Programme, Evangelical Reformed Church of Christ (ERCC), Central Nigeria
A developing CBR programme in a very rural area, starting from scratch.

Village Disability Programme, World Concern, Lao People's Democratic Republic
A rural programme, focusing on vocational training and self help.

'Little Conquerors' programme, Servants to Asia's Urban Poor, Phnom Penh, Cambodia
A community based programme working in an urban slum community.

Services for People with Disabilities, Malaysian CARE, Malaysia
A rehabilitation, training and advocacy organisation, registered with the government.

Community Based Rehabilitation Service, Pokhara, Nepal
A community-based education and support programme working with parents and children.

***Ten Small Steps* video series, MediaHouse, Cairo, Egypt**
A video series produced for parents and professionals to challenge prejudices and provide practical suggestions for the support of children with intellectual disabilities.

BY WASAN SAENWIAN, DIRECTOR

Community Based Rehabilitation and Day Care Programme

Christian Care Foundation
Nakhonpathom Province and Bangkok, Thailand

Tearfund Partner

Also see CCD case study of residential programme in *Children at Risk 5: Children and Residential Care and Alternatives*.

ORGANISATION

Christian Care for Children with Disabilities (CCD) was set up in 1997 as a government approved Thai Foundation. It took over the work originally set up by Christian Outreach (CORD) in 1986 working in the government home for babies, which is actually for children between 0–7 years old.

CONTEXT

Superstition and ancient traditions mean that people believe that disability is the result of past sins in this or a previous life.

Children with disabilities in Thailand especially the mentally handicapped and those with severe physical deformities, generally experience severe discrimination in all areas of life. Superstition and ancient traditions mean that people believe that disability is the result of past sins in this or a previous life.

Many children with disabilities are unwanted by their parents and are therefore abandoned. Some of these end up in hospitals and many die prematurely. The Thai government's response to the problem was to establish three different children's homes in a suburb of Bangkok, admission depending on age and disability. Of those children who are able to stay with their families, some are left at home by themselves for much of the day, and others are physically maltreated.

CCD is responsible for a day centre at the government home and a small residential unit called Rainbow House which also has day care for children with disabilities from the local community. CCD has also been developing a Community Based Rehabilitation (CBR) programme Kamphaeng Saen, Nakhonpathom Province (60 kilometres west of Bangkok). It recognises that residential care has a relatively low coverage rate compared to a community approach.

DEMONSTRATING GOOD PRACTICE

A comparative survey of the needs of children with disabilities, conducted by CCD with Handicap International, in a rural and an urban area, found that families in the rural area were more likely to be optimistic about the child's future. Urban families, on the other hand, felt that the solution for a child with disabilities was to put them in a home. CCD felt that this was due to the breakdown of traditional values in the urban setting.

An experienced man who trained in India heads the CCD programme up. He is well aware of the spiritual needs of the family, and sees children and their families in a holistic way. Praying with families is an integral part of the work. On an individual level, the emphasis of the relationship approach to parents means that the needs of the whole family are taken into consideration.

The CBR programme works in close co-operation with the local Disabled Persons Organisation to represent the interests of children and other people with disabilities in the community. CCD is a member of the Federation of Health Voluntary Organisations. The CBR programme is seeking to work with district health and education authorities. Relationships are also being developed with the local church.

Usually relationships between parents and children with disabilities stop as soon as they are transferred to the government home. CCD try to trace families, especially of those with minor disabilities. Often the process of tracing is done by contacting local church pastors in the district where the parents were last heard of. A programme worker then approaches parents and after careful explanation, showing photos and describing the progress of the child, many parents are willing to be reunited. CCD then spend time preparing both children and parents so that they can live together again. In cases where parents cannot be found, adoption is sometimes possible into a new family.

THE FUTURE

CCD are considering how they can:

- develop the CBR programme to involve children who are less able in decision making
- increase awareness in the local church and community about disability, fostering and adoption
- become less dependent on outside financial support.

Questions to reflect on

- *How has CCD considered the cultural and religious context of child/family/community?* (PRINCIPLE 6.5)
- *How does your programme take into consideration the child's cultural context?*
- *How does CCD lobby and intercede for children at local level?* (PRINCIPLE 7.1)
- *What are the issues in your context that need addressing? How could you lobby on behalf of children or involve parents and children?*
- *How does CCD dialogue with parents so that they can make informed decisions about their children?* (PRINCIPLE 7.4)
- *In your programme are parents seen as a nuisance or as an integral part of the programme?*

BY JANE TOMPSETT, FORMER INTERNATIONAL PERSONNEL WORKER WITH TEARFUND, SECONDED TO ERCC

Community Based Rehabilitation Programme

Evangelical Reformed Church of Christ (ERCC) Central Nigeria

ORGANISATION

The Sudan United Mission founded the ERCC in 1916. Today, under national leadership, it is committed to evangelism and training believers in discipleship. It has a theological seminary and a college for pastors and a Theological Education by Extension programme (TEE). On the medical side the ERCC church runs a comprehensive health centre in Alushi with 30 dispensaries, and a training school for community health extension workers. The Alushi medical centre is a base for many community outreach programmes: child welfare clinics, AIDS support and education programmes and a voluntary village health worker programme. In January 1997 the ERCC church launched a Community Based Rehabilitation (CBR) programme.

CONTEXT

- It is estimated that 4% of the population of Nigeria is handicapped, either physically (70%) or mentally (30%) based on Hellender (see above).
- Before the programme started, the area had no disabled peoples' organisations so it was felt that there was no real choice except to start the programme with health workers as part of a medical service.
- The expectations within the local community of what a person with a disability could do were low.
- In Nigeria, nationally, according to UNICEF only 32% of children receive poliomyelitis vaccination. Hence the disease is still endemic and is the largest cause of disability in children.
- Only ten of the 62 children with disabilities were attending primary school.
- Eye problems accounted for over 50% of the CBR work.

THE COMMUNITY BASED REHABILITATION (CBR) PROGRAMME

The aim of the programme is to identify people with disabilities of all ages and to encourage and empower them to take part in family and community life.

The aim of the programme is to identify people with disabilities of all ages and to encourage and empower them to take part in family and community life. It is also to share the love and good news of Jesus with them.

ERCC employed an experienced health worker and church elder. He worked with an experienced expatriate and visited a number of CBR programmes run by other NGOs to explore possibilities. Eight local people were recruited as field workers. They were all qualified as junior community health extension workers. Several had parents with disabilities so they had a natural empathy and understanding of some disability issues. The field workers were given three weeks training in disability issues and started a TEE course on discipleship. They were then invited to join church outreach teams in the villages and were given a bicycle to enable them to visit their clients with disabilities.

DEMONSTRATING GOOD PRACTICE

Early in the programme there was a recognition that the clients were the experts and that the most important role of the workers was to listen to them.

- Early in the programme there was a recognition that the clients were the experts and that the most important role of the workers was to listen to them.
- Dialogue with parents of children with disabilities to send children to school.
- Dialogue with teachers who have accepted children with disabilities into their class.
- Dialogue with health services leading to provision of preventive and curative medical eye services, including glasses and promotion of immunisation of children.
- Mobility aids for those with polio are encouraged especially for those who would otherwise only crawl.
- Local craftsmen were taught to make callipers, skateboards (to sit on) and hand driven bicycles.
- The community-based approach encourages active participation of families of a child with disabilities and requires minimal infrastructure. It therefore creates less dependency and is more sustainable.
- The service is low in overheads and movable, as the field workers use the church as a base, so require only a bicycle and a lockable cupboard.

Questions to reflect on

- *How does ERCC involve and help children's parents in the programme?* (PRINCIPLE 6.2)
- *How do you involve parents in assessing needs, evaluating results etc?*
- *How does ERCC network effectively with other organisations at local level (including those of other sectors, eg education and health)?* (PRINCIPLE 6.4)
- *How could your organisation network more effectively?*

BY NIGEL POULTON, FORMER TEARFUND INTERNATIONAL PERSONNEL WORKER, SECONDED TO VDP

Village Disability Programme

World Concern, Lao People's Democratic Republic

Tearfund Partner

ORGANISATION

World Concern is a Christian humanitarian agency with a concern for the needy people of the world. It specialises in self-help development, health care, emergency relief and rehabilitation programmes in developing countries. World Concern has been involved in the Lao PDR since May 1981. It strives to bring hope to the poor and marginalised by focusing on four areas of response: food security, primary health care, clean water and income generation.

CONTEXT

Their communities and village society often marginalise individuals with disabilities. They are tolerated by their family and neighbours but, as a result of their disability, they are perceived as having little value and little to contribute to the family or community. Children with severe disabilities are left to die of preventable diseases. Adults with disabilities find themselves living on the edge of society, treated as outcasts. People with disabilities may include individuals who:

- are partially or totally blind
- have problems with hearing or speaking
- have problems with moving
- are lower extremity amputees
- are upper extremity amputees
- have disabilities of neurological origin such as cerebral palsy, polio, hemiplegia, paraplegia, and quadriplegia
- show strange behaviour
- have seizures
- have learning difficulties.

Families of people with disabilities find themselves caught in the cruel dilemma of caring for the one with special needs or caring for the whole family.

Families of people with disabilities find themselves caught in the cruel dilemma of caring for the one with special needs or caring for the whole family.

THE PROGRAMME

The goal of the programme (entitled DIGNITY – Disabled persons Income Generation and New IdentiTY) is to establish a model appropriate to the Lao context which recognises the dignity and lives of women, children and men with disabilities by providing opportunities for them to help themselves.

The purpose is to:

- improve health and increase the person's ability in self care and hygiene
- increase the capacity of a person with disability to make choices by participating in a Rural Dignity Group.
- increase the level of food security and income generation capacity of a person with disability.
- inform children and parents of their basic civil rights within Lao society.

These purposes are achieved by two strategies:

- **Village Based Rehabilitation** (VBR). Mobile teams visit persons with disabilities to train and monitor rehabilitation therapies implemented by the primary care givers. We have trained three Lao physiotherapists who are highly skilled in facilitating rehabilitation and primary health care. Examples of appropriate assistance would be encouraging a family to put a railing up around the outside of the house so that a person with disabilities can move more easily, or demonstrating how a child with disabilities can sit in a chair for certain periods each day, rather than lying on a bed continually. At least 50 new persons with disabilities and their families have participated in training and follow up in self care skills and hygiene.
- Persons with disabilities and their families are encouraged to organise themselves into **Rural Dignity Groups**, each with a minimum of nine members. World Concern staff use participatory methods to stimulate the groups. As the women, children and men with disabilities relate to each other, their sense of value and dignity increases. In 1998 there were 50 families participating in income generating activities, but on an individual basis. So these individuals and the 50 new VBR persons were encouraged to meet in the Rural Dignity Groups.

The programme seeks to go beyond simply providing credit, with complementary and co-ordinated investments in income generation, health, legal rights and capacity building. As skills are developed, group participants can plan their own integrated development strategy. They will be able to act as their own advocates in claiming rights, benefits and services provided by the government, as well as confronting injustice. Persons with disabilities can, for example, participate in functional literacy courses. Groups will decide themselves on meeting procedures. They will determine

their needs and collectively address two of the most common problems which they cannot do individually, namely food and income generation.

DEMONSTRATING GOOD PRACTICE

Persons with disabilities are empowered to act as their own advocates in gaining access to rights, services and facilities hitherto beyond their reach.

Participants with disabilities can demonstrate permanent increased functional abilities. Families then regard the member with the disability as a person who is able to participate in and contribute to family activities. Training is offered in such areas as health, law (human rights, land rights, inheritance etc), finance, leadership skills etc. The programme builds self-reliant, empowered, indigenous Rural Dignity Groups that are not dependent on a constant infusion of resources from the outside. Above all, the persons with disabilities are empowered to act as their own advocates in gaining access to rights, services and facilities hitherto beyond their reach.

Through their own experiences, people with disabilities are discovering that there are ways that they can do more to care for themselves and their families. Small improvements can give birth to hope. As people with disabilities are more able to communicate their thoughts and needs, and understand and respond to others, attitudinal changes occur. Rural Dignity Groups run by these empowered women, children and men serve as a catalyst for just, sustainable development. These groups can ensure that other groups form and grow, facilitating replication at both provincial and national levels throughout the Lao PDR.

Questions to reflect on

- *How does training of staff in communicating with children and their families help World Concern meet the needs of children more effectively?* (PRINCIPLE 4.2)
- *How could you develop your training of staff?*
- *How does World Concern consider the spiritual, physical, mental, emotional and social (including educational and vocational) aspects of child development?* (PRINCIPLE 4.3)
- *Which areas do you over/under emphasise and which do you need to develop further?*
- *How does World Concern ensure there is dialogue with parents and children so that they can make informed decisions and represent their own interests?* (PRINCIPLE 7.5 and 7.6)
- *How could you empower children and parents in this way?*
- *How does the programme change attitudes and behaviour towards people with disabilities?*
- *What are the attitudes and prejudices that exist in your situation? What could you do to change them?*

BY DR SUE JACK,
PROJECT
CO-ORDINATOR

'Little Conquerors' Programme, Servants to Asia's Urban Poor

Phnom Penh, Cambodia

Tearfund Partner

ORGANISATION

Servants have been working in Cambodia since 1993 under a contract with the Royal Government of Cambodia. We participate with the poor in seeking the relief of suffering and community development to bring hope and justice. We recognise the resources the poor have to contribute to their own development and seek to facilitate (but not control) this process in which the poor become responsible for their own development. We focus on the poorest of the poor and most marginalised in an urban district of 120,000 people in Phnom Penh, which includes children with disabilities. We are an international Christian community called to serve among the poor, seeking to work out our holistic mandate in the local context through our work in health and community development. We seek to see God's compassion and healing transform the lives of the poor communities in Phnom Penh.

CONTEXT

Disability is often regarded as due to bad 'karma'

In Cambodia it is estimated that 95% of people are Buddhist, and so disability is often regarded as due to bad 'karma', either of the parents or the child. There are social and financial disadvantages along with this, as well as the feeling of helplessness that this is 'fate' and therefore nothing can be done about it. Families may have tried to seek help for their children from traditional healers but been unsuccessful, and this decreases their motivation to seek help from the fledgling disability services that are now appearing in Cambodia. The sense of fatalism and 'unfortunate destiny' means that children are often 'hidden' from view in the back of the house and at times neglected, so finding children needs to be very proactive.

DEMONSTRATING GOOD PRACTICE

Our project, 'The Little Conquerors', is a community-based rehabilitation project for children with disability in Mean Chey District. An initial survey in 1993 identified 2.9% of children had some disability in our health district although this was thought to be very under reported. At the time there were no other services being offered in our area. Initially an expatriate occupational therapist worked with a Khmer medical

assistant counterpart to set up the project. Two Khmer workers who have received local training in CBR, now run the project with some expatriate doctor input.

We network extensively with other agencies and much of the work is facilitating children being seen by experts for assessment and being fitted with aids (braces, wheelchairs etc). We use a functional basis for assessment and therapy and always use locally produced appropriate technology, eg special chairs, walking rails, ramps.

We try to get the children into mainstream schools if possible.

We try to get the children into mainstream schools if possible. We lobby at the local schools on their behalf and provide any equipment necessary to make mainstreaming possible, eg building ramps. Once a week we have a therapy/play session where caregivers are taught appropriate exercises. Reinforcement and teaching of good caring practice for their children is also given.

We stress that it will be the caregivers' commitment to the child that will help the child improve, not our expertise, and that it will be a long slow process. We therefore do all we can to provide ongoing support to the whole family, making sure they understand advice given, eg for exercises and how to follow it. It is also a great opportunity for families to meet one another and we often try to facilitate links between old families and new to encourage each other in what progress is possible. This speaks much louder and has much more impact than anything we can say.

We stress that it will be the caregivers' commitment to the child that will help the child improve, not our expertise.

Much of the programme is focused on home visitation of the families, where issues can be discussed relating to all aspects of life. We see Khmer, Cham (Muslim) and an increasing number of Vietnamese children, as one of our staff speaks fluent Vietnamese. Our health district has a significant number of Vietnamese families who are socially marginalised and often have difficulties accessing health care in Cambodia.

THE FUTURE

We hope our CBR project will continue to reach the children with disabilities in our district. We want to be more proactive in the future in pressing for such children to be in mainstream schools. We also want to use this as an opportunity to teach the teachers and the other students about disability in the community. One emerging problem is that of AIDS orphans, in particular orphans with disabilities who have the double stigma of a disability and being in a family with AIDS. We are just beginning to trial fostering these orphans with families from our children's disability programme who are already used to looking after a child with disabilities. This avoids the need for placing children in orphanages (who have refused to take them anyway) and keeping them in the community. We also intend to explore further income generating options. One such option may be the setting up of small scale vegetable or animal raising projects in which families could participate co-operatively.

Questions to reflect on

- *How do Servants involve and impact the children's parents, carers and families?* (PRINCIPLE 6.2)
- *How can your organisation involve parents/carers/families more effectively?*
- *What consideration do Servants give to the cultural and religious context of the child, family and community and how does this affect their care?* (PRINCIPLE 6.5)
- *Do you take cultural and religious beliefs into account and how does it affect the way that you manage your programme?*

BY CHRISTINE FOO,
DIRECTOR

Services for People with Disabilities

Malaysian CARE, Malaysia

ORGANISATION

Malaysian CARE is called to be the visible expression of the holistic mission of Christ to a broken world, displaying his love, compassion and justice to the poor and socially deprived. Malaysian CARE believes that the community of God's chosen people is a visible evidence of His presence in the world. Therefore, we seek to assist Christians to fulfil the biblical mandate.

Malaysian CARE is a registered social welfare organisation, providing services in the following four areas:

- Children and Families Services
- Mental Health Services
- Drugs and Prison Rehabilitation Services
- Services for People with Disabilities.

In 1982, Rumah Rahmat (or House of Mercy) was set up as a home for disabled children who are severely physically handicapped. However, as a family-style residential facility it could only cater for a small group of disabled children/adults. The staff went to the surrounding community to provide help to disabled children/adults at home.

CONTEXT

Malaysia is a multi-cultural, multi-religious country with a population of 19 million people. The Malaysian Government says that 1% of the population have some form of impairment as opposed to the World Health Organisation's estimate of 10%.

REGISTERED NUMBER OF DISABLED PEOPLE IN MALAYSIA

Registration of disabled people with the Department of Welfare is voluntary. The registered number of disabled people is as follows:

CATEGORIES	NATIONAL FIGURES
Blind	10,416
Deaf	19,358
Physically handicapped	10,197
Mentally retarded	15,702
TOTAL	**55,673**

Source: Government of Malaysia Department of Social Welfare (June 1995)

Institutional care has been the key service provided by the Social Welfare Department for disabled people. In 1994, five institutions were run by the Department providing long-term care to 706 people with learning difficulties (Malaysian Government Department of Statistics, 1995).

The service provision for disabled people falls short of needs and demands, be it in education, vocational training, rehabilitative and therapeutic services, sheltered workshops, or employment.

DEMONSTRATING GOOD PRACTICE

Besides the small residential home in Rawang (approximately 35km from Kuala Lumpur), the home caring ministry began in the city in late 1982. This involved giving practical help, for example: visiting patients who needed after-care in their homes, bringing disabled children for physiotherapy, helping teenagers to get birth registration and identity cards so that they could get to work.

This has developed into Home Caring Resource Services with a professional staff team. The emphasis is on staff training, and the sharing of resources, equipment and knowledge with others working amongst disabled people.

Many young people with learning difficulties just stay at home.

The Toy Library and Resource Centre was to be one of the support services to disabled people and their families. Through the home visits, the staff were made aware of the many young people with learning difficulties who just stay at home. From what was to be just a weekly meeting for young disabled adults to socialise (that is, Social Clubs), the realisation of the potential developed into a more structured training programme, called Day Training Centres (DTC).

DTC runs training programmes for adults with mild to severe learning difficulties, aged 16 to 35. The primary aim of the DTC's training programme is to equip persons with learning difficulties with the daily living skills (self care) and social skills

for greater independence at home and in the community. This will allow them a degree of dignity and self-respect and reduce the burden to their families and society.

Continuing with the community home visits in Rawang, CARE began with concerted efforts to develop the work of community-based rehabilitation (CBR) as a separate entity from the residential home in 1989. Besides the weekly day training classes for disabled children/young adults, there are two different playgroups once a month for children who have severe or multiple handicaps.

Through liaison with the Welfare Department and government clinic doctors, staff have been able to facilitate the process of registration with the Welfare Department for the families of the disabled.

Services for People with Disabilities (SPD) did not want to duplicate existing services but rather to focus on new areas of provision or unmet needs. A survey of existing service provision in the country revealed that there were no early intervention programmes and no special training programmes for those over the age of 18 except for institutional care.

The aim of the programme is not just to train the child, but also to enable the parent/carer to help the child.

The Early Intervention Programme (EIP) is a programme designed for young children (0–6 years) who have developmental delays. The aim of the programme is not just to train the child, but also to enable the parent/carer to help the child. This programme also helps the disabled child to learn and to be able to integrate into regular kindergartens and be better prepared for school at six years old.

People with learning difficulties can learn when opportunities are given to them.

The mission statement of SPD is to strive to extend God's love to the community by developing and implementing support services for people with disabilities – in particular, persons with learning difficulties – so that their full potential may be realised. Our programmes are community-based, training oriented and designed to enable people with learning difficulties to achieve maximum independence and enhance their quality of life. Furthermore they aim to equip disabled people to be a potential workforce, helping them to meet their aspirations for employment and uphold their dignity. What moves us to concentrate our efforts on training people with learning difficulties is the fact that they can learn when opportunities are given to them.

SPD collaborates with other agencies (government and non-governmental). We work closely with the families of the disabled child/ young adult. Assessments and individual education plans are made in consultation with the parents. CARE has encouraged the parents to form their own family support group. This was registered as the first independent family support group, PERKOBP, and full membership is open only to families who have a disabled person. CARE's SPD has helped PERKOBP with employment training for people with learning difficulties, through its Employment Training Centre and sheltered workshop.

THE FUTURE

Malaysian CARE has pioneered the EIP in Malaysia. Our aim, in partnership with churches is to to set up more services, be they EIP, DTC, social clubs, employment training, sheltered workshops, special Sunday Schools, HandiCamps, or respite care services. We believe that the more localised these services are, the better it is for disabled people. We have not set up more direct services on our own. Rather, SPD's role is to assist other groups, especially the churches, to set up services, to provide technical know-how and knowledge, and to provide staff training or placement exposure. Another key area is to develop resource materials (curriculum, videos, training packages). Networking, collaboration, professionalism, staff development and advocacy are all ways of working to provide effective services for people with learning difficulties.

Questions to reflect on

- *How have Malaysian CARE been involved in lobbying and interceding for children with disabilities at local level and what were the results?* (PRINCIPLE 7.1)
- *What are the issues and how could you be involved in lobbying and interceding for and with children in your programme?*
- *How do Malaysian CARE ensure there is dialogue with parents so that they can make informed decisions?* (PRINCIPLE 7.4)
- *How do you involve parents in your programme?*

BY JANE SCHOFIELD-GURUNG

Community Based Rehabilitation Service (CBRS)

Pokhara, Nepal

ORGANISATION

CBRS is a locally registered NGO, and is affiliated to the Social Welfare Council, the government 'umbrella' for international organisations and NGOs in Nepal. It was set up in early 1995 and the project started work in April 1995. CBRS is not a specifically Christian organisation, but four of the seven Committee members (all locals), and some of the staff (including the main founder) are Christians, and certainly the working style and philosophy represent Christian values. CBRS was started to meet the wider needs of physically disabled people and their families, as no other organisation or services were available to do so.

CONTEXT

Generally rates of disability are estimated at 4–10% of the population. The main problems faced by disabled people are:

- **Practical** For example, families who have to work all the time to grow food have little time to help a disabled child. The mountainous terrain means many villages are accessible only by walking, thus isolating many disabled people and preventing them getting assistance.
- **Social** For example, there are the negative attitudes of others (sometimes including family members), the lack of opportunity to take part in family or community activities, and also blame given to parents (particularly mothers).
- **Educational/vocational** Most disabled people do not get access to education or work opportunities.

Also in the wider Nepali context, the general population currently faces worsening economic problems, and poor health and education services.

DEMONSTRATING GOOD PRACTICE

The main activities of CBRS are:

- promoting awareness (especially in local groups/communities/schools)
- parents groups (for self help, support, training, and management of own funds)

- home visits to disabled children within our field programme area, for practical and moral support to them and their families
- weekly counselling day (for children from outside the project area and for our clients who need special advice eg from physiotherapist/speech and language therapist)
- networking (with other organisations working in the disability and community development sectors, both locally, nationally and internationally)
- advisory group (part of the project management, including disabled adults and parents of disabled children)
- training of parents, CBRS and other organisations staff
- acting as a resource organisation for others
- more recently there has been more focus on income generating opportunities for clients and families, education placements, school awareness and teacher training.

As of June 1999 we see about 250 clients regularly in the home visit programme, and we have 22 full time and eight part time staff.

Employing disabled people and doing awareness programs in schools has begun to challenge attitudes and stereotypes.

We pay a lot of attention to awareness, and the need to change attitudes and stereotypes if the long term situation is to improve. Employing some disabled people as staff members, doing awareness programmes in schools, and networking with local clubs such as the Rotary are examples of this.

Parents and adults with disabilities are involved in identifying needs and priorities, via feedback from parents groups, home visits, and the advisory group. We focus on activities of daily living in the home visits, and setting of progress goals for clients. Also through the parents groups, advocacy and peer support is developing. Two surveys have been done to assess the parents' level of satisfaction with the services offered. These have included the progress of children as evaluated in their terms.

We also feel that CBRS shows good practice in terms of staff issues, such as selection criteria, supervision, training and development. We have seen progress in our own performance as an organisation and as individuals, shown for example by an increasing number of individuals and organisations using our resources. We can see development of the parents' groups as they take up their own advocacy and fund raising, and a developing partnership as we combine for more activities.

A PARENT'S QUOTATION AT A MEETING

'NEW' PARENT: *I am new, so I would like to know what this organisation will do for us and our children?*

'OLD' PARENT: *You should understand this: we do the work and they help us to do it. Our children are our responsibility. They help us to do the things, they don't do it for us.*

That sums up our work in participation very nicely!

THE FUTURE

This is probably the hardest section to write about. We have many things which we would still like to develop:

- more income generating/vocational opportunities
- increasing emphasis on education opportunities
- continuing work on awareness and on early detection of disabilities
- helping other organisations incorporate disability work and issues into their working
- continuing of the processes of 'developing and enabling' which we experience with our clients, families and ourselves as well.

At the moment the biggest challenge we face is funding. We are doing an increasing amount of local fundraising and activities from the project to help this. However, these are very time-consuming. We also find that disability, especially when not approached from a 'charity' aspect, is not very attractive to donors! We think that to do good quality and lasting work takes resources, and this is true of any system that supports disabled people anywhere in the world. We agree that we should work towards 'sustainability' and diversify our sources of support. But it is also true that if we work in a truly community-based way then this kind of development takes time. Therefore, in the early stages financial support is needed and donors need to understand this.

Questions to reflect on

- *How does CBRS involve children and their families in identifying needs?* (PRINCIPLE 4.1)
- *How could your programme involve children and their parents in this process?*
- *By what means are the children's immediate community involved in the CBRS programme and encouraged to challenge stereotypes?* (PRINCIPLE 6.3)
- *How can you most effectively influence your communities' attitudes for the good?*

'Ten Small Steps' video series

MediaHouse, Cairo, Egypt

ORGANISATION

MediaHouse is a production house committed to producing high quality videos in the Middle East and is registered in Egypt as a limited liability company. Caritas-Egypt established the SETI (Support Education Training for Integration) Centre in 1986 in collaboration with the Ministry of Social Affairs in answer to the persistent need for trained special educators in the field of mental handicap, as it was then known.

MediaHouse and Caritas-SETI have co-produced a series of professional educational videos in Arabic about intellectual disabilities. It is designed for families in Egypt who have a child with an intellectual disability. The aim of the series is to stimulate a positive attitude towards those with intellectual disabilities and to give practical information to parents about how they can best raise their child.

CONTEXT

According to the Central Office for General Statistics, over 1.5 million people in Egypt have an intellectual disability. Other indications suggest this is a conservative figure. Of these people, only a few thousand have access to some sort of support.

According to the professionals and parents interviewed, video is a valuable tool in educating people about intellectual disabilities. The vast majority of people with intellectual disabilities live in the communities into which they were born. Most of these individuals are never given the opportunity to step into the outside world. The question for them is whether any significant services will reach them during their lifetime.

Most homes in Egypt possess a television, and most people have access to a video player in their community. Due to the stigma attached to intellectual disabilities, videos are the ideal way to disseminate information about such a culturally sensitive topic. No 'intervention' in the home from outside is required. Videos bring services into the home at a minimal cost. MediaHouse and Caritas-SETI consider this situation an unrivalled opportunity to see education transform the lives of countless individuals. It is hoped that the content of the videos will encourage parents, in particular, to bring their child out of the home and into the community where he or she can gain acceptance.

Video is an ideal means of communicating to a largely non-literate target group.

Video is appropriate for another reason. Our research has found that it is women who largely carry the burden of caring for people with intellectual disabilities. However, according to UNICEF only 34% of women are literate in Egypt. Written literature has a small audience whereas television and video are widespread in all levels of Egyptian society. Video cassettes therefore would seem an appropriate means of communicating to a largely non-literate target group.

There is nothing available on video in Arabic that is specifically designed to support families caring for a person with an intellectual disability in the Middle East. Several western videos have been used by centres in Egypt for educational purposes, but their foreign look and feel has not challenged the negative attitudes that are embedded in the fabric of Egyptian society.

THE TEN VIDEO PROGRAMMES

PROGRAMME 1 challenges some of the cultural myths surrounding intellectual disabilities and emphasises the importance of the whole family accepting the child.

PROGRAMME 2 concerns the general medical aspects of intellectual disabilities which doctors, health advisors and parents frequently want to know, including commonly related medical conditions.

PROGRAMME 3 concerns the importance and role of play as a tool of development throughout the life of a child with intellectual disability.

PROGRAMME 4 concerns early intervention (0–7 years) and the importance of a practical programme for the family to use to stimulate the child using all five senses, and develop his or her gross and fine motor control and strengthen the muscles.

PROGRAMME 5 concerns early intervention (0–7 years) and focuses on the child's receptivity to language and his or her communication.

PROGRAMME 6 concerns early intervention (0–7 years) and focuses on the development of personal and social skills, including achieving independence in eating, dressing, washing and toilet habits.

PROGRAMME 7 focuses on leisure and recreational activities as a way to consolidate the skills learnt in 4, 5 and 6 above. It looks at encouraging self expression in the areas of handicrafts, music, art, drama and sport.

PROGRAMME 8 concerns the education of the child as the natural follow-on from early intervention including pre-academic and academic skills and the necessary preparation for work.

PROGRAMME 9 looks at the adult life of the person including employment and the opportunities for work within the government scheme. It also considers how times of change eg marriage and bereavement can affect him or her.

PROGRAMME 10 looks at community-based rehabilitation (CBR) in Egypt, explaining the service delivery model and the mobilisation and maximum utilisation of local resources – not least the person with intellectual disabilities.

DEMONSTRATING GOOD PRACTICE

Short realistic dramas challenge viewers to examine and reflect on their own attitudes and prejudices

The programmes were made in a modern documentary style where children with intellectual disabilities and their families narrate their own stories and experiences. Short realistic dramas challenge viewers to examine and reflect on their own attitudes and prejudices towards people with intellectual disabilities and the cultural issues raised. Viewers will readily identify with the situation and characters and thus find it easy to absorb information.

THE FUTURE

Because of its emphasis on medical aspects (Programme 2) and practical care (Programmes 4, 5, 6 and 7), the series will also be of benefit to those working in hospitals and centres for people with intellectual disabilities. MediaHouse and Caritas-SETI hope that it will become a standard source of reference in such centres throughout Egypt.

Given that the production is culturally authentic and the fact that Egyptian programmes are popular throughout the Middle East region, the series should appeal to other Arabic speaking countries such as Sudan, Syria, Jordan, Iraq and throughout the Gulf area. In these countries people with intellectual disabilities suffer from similar demeaning societal attitudes and ignorance.

Questions to reflect on

- *How does this MediaHouse production ensure that children's abilities and needs are taken into consideration?* (PRINCIPLE 5.1)
- *Does your approach get the right balance between the resilience of the child and their vulnerability?*
- *How does MediaHouse ensure that the child's community is involved and impacted by the video?* (PRINCIPLE 6.2)
- *In what creative ways can you involve and impact your community?*

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SECTION 4

Reflective Question Tool

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4 *The Reflective Question Tool*

This Reflective Question Tool, derived from the Guidelines for Good Practice, is designed to help evaluate any programme working with children with disabilities.

PRINCIPLE 1 BUILDING RELATIONSHIPS

- How is priority given to building relationships – with the child, family, community, organisation or institution and between organisations?
  - Are children with physical disabilities seen to be as capable of participating in decision making as non-disabled children of the same age?

PRINCIPLE 2 PARENTAL RESPONSIBILITIES

- How does the programme encourage the development of parental responsibilities towards children and a caring, child-friendly community?

PRINCIPLE 3 WORKING AT DIFFERENT LEVELS

- At what level(s) does the programme work and how does it consider other levels?
  - Individual
  - Peer
  - Family
  - Organisational/Institutional
  - Community
  - National
  - Policy/Political
  - Spiritual

PRINCIPLE 4 IDENTIFYING NEEDS AND PRIORITIES

- How are children's (and parents') needs identified? How have children and parents been listened to and involved?
  - How does the programme pursue the child-centred goal of compensating for the loss of the child's sensory, cognitive and motor facilities (ie adaptation to the impairment)? How does the programme try to optimise the ability of the child to perform a range of activities within their home and community environments (ie adaptation to the disability)?
  - Is there an assessment of the child's difficulties by function rather than on a medical basis?
  - Are families' own perceptions of their needs assessed?
  - How does the programme take into consideration that each family has its own needs, and that those needs will change over time?
  - Is consideration given to the needs of individual family members as well as the family as a whole? Are the strengths as well as the needs of the families considered?
  - Do families share in the care of the child with disabilities, or is it assumed that it is entirely the mother's responsibility?
  - Can families decide for themselves the level of involvement they feel able to commit to programmes?
  - Are families enabled to identify their own needs and develop their own solutions?
  - Can they then participate in those solutions (rather than professionals doing it)?
- What experience and training do the staff have in communicating with children and their families and facilitating children's participation?
  - Are staffing levels and training needs regularly reviewed? Are all staff working with children trained in how to communicate with children and their families and how to facilitate children's and parents' participation?
  - Where communication difficulties exist is the carer who is most able to communicate with the child sought out to 'translate' and speak for them?
- How does the programme meet the spiritual, physical, mental, emotional and social (including educational and vocational) aspects of the child's development?
  - Is low cost appropriate technology, made by local artisans, used in the design of toys and equipment?
  - Whilst the programme may ostensibly focus on one area (eg a physical or mental disability) are other needs – spiritual, physical, mental, emotional and social – taken into account?

PRINCIPLE 5 CHILDREN'S PARTICIPATION

- How does the programme take into account children's abilities?
- Does it look at abilities and not just at disabilities? Does it take into account children's resilience as well as their vulnerability?
  - Is there any prejudice based on gender, age, parentage, ethnicity, caste or social class, religious background and type of disability?
  - Are children with physical disabilities seen to be as capable of participating in decision making as non-disabled children of the same age?
- How do adults listen to and collaborate with children acccording to their age and ability, individually and collectively in things that affect them?
  - Are creative ways of involving children in how the programme runs being sought? Is there an assumption that they can and should be involved?

PRINCIPLE 6 CHILDREN IN CONTEXT

- To what extent is the child considered in the social, political and historical context of their community?
  - Does the programme include institutional care? Is this seen as the only option or as one of a range? Is there an underlying philosophy that residential care should, where possible, be replaced by community-based rehabilitation?
  - Are children, including those with disabilities, encouraged as valued and contributing members of their family and their society? Does the programme seek to put the child in the context of their community rather than removing them from it? Are the centres set up for children with disabilities seen as separate from the community or part of it?
- How are parents, caregivers and families of the children involved and impacted?
  - Where it is known, are parents/caregivers given an accurate diagnosis and prognosis and kept as informed as possible by all those involved in the care of the child with disabilities?
  - Does the programme avoid labelling families? Does it seek to educate professionals and where possible the public? (See Advocacy section)
  - Is there awareness of the practical factors (eg lack of money, time, energy, support) and attitudinal factors (eg overprotection or neglect) which might hamper family involvement?

- Does the programme help family members adapt to their general circumstances including the child's disability? Does it try to encourage an optimal home environment for the child's development and functional progress?

■ How is the child's community involved and positively impacted?

- Are prejudices and stereotypes of disability being challenged?

■ In what ways are links developed (networking) with other local, national and international organisations (including organisations of other sectors)?

- Is collaboration sought with schools so that children able to benefit from schooling can do so?
- Has a disabled people's organisation been formed which can network and lobby with the children and families?

■ How is the cultural and religious context of the child, family and community taken into consideration?

- How does the programme challenge fatalistic beliefs and negative superstitions associated with specific disabilities?
- What are professionals doing to bridge the sub-cultural barriers between themselves and families especially where the families are poor and find it difficult to vocalise their concerns and needs? Are professionals aware of the very real gap between their values and expectations and those of the people they are intended to serve?
- Are families of children with similar disability given the opportunity to communicate with each other if they want to?
- How are communities informed and educated about the abilities of children with disabilities to help minimise prejudice and encourage potential?
- Is vocational training available to develop practical skills that are income generating? Is choice limited or broad?

PRINCIPLE 7 **ADVOCACY**

■ In what ways does the programme lobby with or on behalf of children and their families at local, national or international levels?

- Is there an understanding of the need to change social attitudes and practices which marginalise people with disabilities in society?

- Do programmes give opportunities for able bodied children to interact with children with disabilities to help reduce prejudice?
- How is awareness raised and positive attitudes promoted among the general public and professionals working with the people with disabilities? Are people encouraged to reflect upon the situation of those with disabilities and to understand the deeper causes of impairment and disability?

■ Are the programme staff aware of the importance of the UN Convention on the Rights of the Child and other human rights issues and conventions?

- Where there are not the resources for this, are they at least aware of the issues? Are they networking with other groups in this area?

■ What are the barriers to advocacy work? How can these be overcome?

■ Is there dialogue with parents and caregivers to help them make informed decisions and represent their families?

- Are parents, caregivers and families informed how to lobby? Are they given help in seeking changes to service systems so that the family can meet the needs of the child?
- Does the programme involve the carer most able to communicate with the child to translate and speak for them?

■ Is there dialogue with children so that, depending on their age and ability, they can make informed decisions and speak for themselves and their peers?

■ To what extent are the programme staff aware of the biblical basis of advocacy for children and the importance of prayer? How does this affect the way they work?

PRINCIPLE 8 CHILD-SENSITIVE INDICATORS

■ How does the programme measure the impact of its work on children and their families? Do the indicators measure quantitative as well as qualitative impact?

■ Do these indicators show how the programme has an impact on the lives and environment of the children and their families? Is the data broken down into age and gender groups?

■ How are the parents, caregivers and children involved in the evaluation of the child and the care given?

■ How does the programme reflect on and use the results of evaluation?

SECTION 5

References and Resources

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5 *References and Resources*

WHAT TO READ

Key texts

Coleridge, P (1993) *Disability, Liberation and Development,* Oxfam Publications (see below). ISBN 0 85598 194 6

- Case studies in Zanzibar, Zimbabwe, India, Jordan and Lebanon.

Healthlink Worldwide (1998) *We Can Play and Move* (available from Healthlink Worldwide). Single copies **free** to developing countries, £6/US $12 elsewhere. ISBN 0907320 13 9

- Shows play activities that can help a child with disability to improve and co-ordinate movement and balance.

Ingstad, B and Whyte, SR (Ed) (1995) *Disability and Culture*, University of California Press, Berkeley. ISBN 0 520 08362 8

Potter, D (1998) *Am I Beautiful… or What?* (available by Mail Order via Scripture Union Mail Order, PO Box 764, Oxford, OX4 5FJ, UK). ISBN 1 85999 202 1
Telephone +44 (0)1865 716880, Fax: +44 (0)1865 715152.
Post and packing: Europe £3.50, rest of the world £4.50 (surface mail) or £6 (airmail).
Enquiries: Scripture Union UK Schools Unit, E-mail schools@scriptureunion.org.uk

- Information about learning disability, training material for individual or group use, essential guidance on running meetings for people with learning difficulties, a course of teaching materials for such meetings.

Werner, D (1994) *Disabled Village Children: a guide for community health workers, rehabilitation workers and families*, Hesperian Foundation, PO Box 1692, Palo Alto, California 94302, USA. ISBN 0 942364 06 6 (available from TALC in English and Spanish)

Werner, D (1998) *Nothing About Us Without Us* (available from TALC or Hesperian Foundation. Language editions available include Arabic, Chinese, French, Portuguese and Spanish)

- Explores innovative aids that can be made at low cost. It also considers how people with disabilites and those without them can learn together.

Other texts

Abu-Habib (1997) *Gender and Disability: women's experiences in the Middle East*, Oxfam Publications. ISBN 0 85598 197 0 (available from Oxfam)

Ayre, M (1984) *Personal Transport for Disabled People*, Healthlink Worldwide (available from Healthlink Worldwide/TALC)

- Designs from all over the world to encourage the local manufacture of wheelchairs, trolleys and tricycles.

Banerjee, A and Hamblin, T (1995) *Physical Management for the Cerebral Palsied Child,* (available from Anita Varma, Indian Institute of Cerebral Palsy, Spastic Society of Eastern India)

Berglund, AK (1997) *A Matter of Context… the sexual abuse of children with disabilities* Radda Barnen (available from Radda Barnen: Code 1093)

- Describes prevalence and prevention, detection and support strategies.

Black, K (1996) *A Healing Homiletic: preaching and disability*, Nashville, Abingdon

- This book offers a methodology for understanding disability in the life of a congregation. The author discusses blindness, deafness and hearing loss, paralysis, ritual impurity, leprosy, chronic illness, epilepsy, mental illness, and demon possession.

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Boylan, E (1991) *Women and Disability*, Zed Books, 57 Caledonian Road, London, N1 9BU, UK. ISBN 0 86232 987 6

Brolin, LA (1998) *The Rights of Children with Disabilities: how is progress monitored? A review of national and NGO reports to the Committee on the Rights of the Child*, Radda Barnen (available from Radda Barnen: Code 1046)

Carey, J and MacIvor, C (1996) *Implementing Community Based Rehabilitation of Children with Disabilities in Morocco, North Africa*, SCF (available from SCF UK)

- Teaching pack of 24 slides and text in English/Arabic.

Child to Child *Child to Child and Disability* pack (available from TALC)

- Including activity sheets for children to help them prevent and recognise disability and to sensitise them to the problems and needs of children with disabilities.

Eiesland, NL (1994) *The Disabled God: towards a liberatory theology of disability*, Abingdon Press, 201 Eighth Avenue South, Nashville, TN 37203, USA. ISBN 0687108012

- Looks at Jesus being 'disabled' on the cross and then at the meeting with the disciples after the resurrection.

Gartner, A, Lipsky, KL and Turnball, AP (1991) *Supporting Families with a Child with a Disability*, Paul H Brookes Publishing Co. ISBN 1 55766 059 X

Gaventer, W *Dimensions of Faith and Congregational Ministries with Persons with Developmental Disabilities and Their Families: a bibliography and address listing of resources for clergy, laypersons, families and service providers*, Cost US $10 from The Revd Bill Gaventa, The Boggs Center – UAP, PO Box 2688, New Brunswick, NJ 08903, USA. Tel: +1 732 235 9304, Fax: +1 732 235 9330

Griffiths, J, Cunningham, G and Dick, S *Onwards and Upwards: involving disabled children in decision making – a training manual for professionals*, Children in Scotland, Princess House, 5 Shadwick Place, Edinburgh, EH2 4RG, UK. Tel: +44 (0)131 228 8484, Fax: +44 (0)131 228 8585, E-mail: info@childrenscotland.org.uk

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Helander, E, Mendes, P, Nelson, G and Goerdt, A (1989) *Training in the Community for People with Disabilities* (available from WHO, Switzerland. Also in Arabic, Portuguese, French and Spanish)

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Pessen, U (1998) *Children with Disability in Programmes Directed at Children Affected by Armed Conflict,* Radda Barnen (available from Radda Barnen: Code 1086)

Pluyter, B (1989) *Alternative limb making*, Healthlink Worldwide (available from TALC)

- Technical information and advice on the manufacture and fitting of low cost below the knee prosthesis.

Priestley, M (1998) *Childhood Disability and Disabled Childhoods: agendas for research*, Childhood 5 (2) pp 207–223, Author E-mail: m.a.priestly@leeds.ac.uk, Disability Research Unit, University of Leeds

Ransom, JG (1994) *The Courage to Care: seven families touched by disability and congregational caring*, Nashville, Upper Room Books

- Chronicles the stories of people whose lives were dramatically changed by the caring of congregations, friends, and family. Important book for churches wanting to understand why and how caring is part of what it means to be a community and to offer hospitality.

Rieser, R (1995) *Invisible Children: report of the Joint Conference on Children, Images and Disability*, Organised and published by Save the Children and the Integrated Alliance

Save the Children (1995) *In Our Own Words: disability and integration in Morocco.* ISBN 1 899120 21 1

Save the Children (1994) *Children, Disability and Development: achievement and challenge*, Conference Report, SCF, London (video also available)

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- Sobsey has gathered a wide range of resources relevant to sexual abuse and exploitation of people with disabilities. A valuable resource for people concerned with abuse.

Sobsey, D (1994) *Violence and Abuse in the Lives of People with Disabilities*, Baltimore: Brooks

- People with disabilities are often abused by family members, therapists, or caregivers upon whom they are dependent. Their vulnerabilities put them at greater risk of further abuse so they are fearful or reluctant to identify their abusers. Sobsey provides clear guidance for identifying abuse and working to change the social situations that perpetuate abuse. This book is for everyone who works with and campaigns for people with disabilities.

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Stubbs, S (1993) *Disability Resource and Information Pack*, Save the Children (available from SCF UK)

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Taylor, M and McCloughry, R (1998) A Disabled God, *Third Way*, October 1998

Thorburn, MJ and Marfo, K (1994) *Practical Approaches to Childhood Disability in Developing Countries*, Global Ave Publishing, 16057 Tampa Palms Blvd, West #219, Tampa, Florida 33647, USA. ISBN 0 88901 1826

Through the Roof (1999) *Roofbreaker Guides*, Guidelines for involving children with disabilities into church life (available from Through the Roof Ministries UK)

Waljee, A (1989) *I Can Do It Too* (Level 2 reader), Child to Child Trust, Longman. ISBN 0 582 036364 (available from TALC)

Webb-Mitchell, B (1993) *God Plays Piano Too: the spiritual lives of disabled children*, Crossroads Publications

- The stories of children with disabilities who had wonderful, but often hidden, gifts. Webb-Mitchell shows the church how to welcome and receive the gifts and 'reveals the hidden wholeness that lies beneath the broken surface of all our lives'.

Webb-Mitchell, B (1994) *Unexpected Guests at God's Banquet: welcoming people with disabilities into the Church*, Crossroads Publications

- This is concerned with learning how to welcome people with disabilities and why doing so is essential for the Church. 'For it is only when we learn how to be with those who are different from us, and learn how to accept the love of God that we all need, that we will be able to sustain a community that is capable of worshipping God.'

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Wirz, S and Winyard, S (1993) *Hearing and Communication Disorders*, Macmillan Press. ISBN 0 333 57448 6 (available from TALC)

- For community-based rehabilitation workers and trainers.

Young, F (1997) *Encounter with Mystery: reflections on L'Arche and living with disability*, Darton, Longman and Todd. ISBN 0232522324

- Group of essays of theologians after visiting the L'Arche communities.

WHO TO CONTACT

Action in Disability and Development (ADD), 23 Lower Keyford, Frome, Somerset, BA11 4AP, UK. Tel: +44 (0)1373 473064, E-mail: add@gn.apc.org
Contact: Beverley Ashton

- To strengthen DPOs and give advice to NGOs working with inclusivity.

Baptist Union of Great Britain, Baptist House, PO Box 44, 129 Broadway, Didcot, Oxfordshire, OX11 8RT, UK. Tel: +44 (0)1235 512077, Fax: +44 (0)1235 811537, E-mail: 100442.1750@compuserve.com

Bernard Van Leer Foundation, PO Box 82334, 2508 EH The Hague, The Netherlands. Tel: +31 70 351 2040, Fax: +31 70 350 2373,
E-mail: registry@bvleerf.nl Website: www.bernardvanleer.org

- Research and publications on resilience in children.

BOND (British Overseas NGOs for Development) Disability and Development Working Group. Contact: Emanuela Brahamsha of Sense International, Regent's Wharf, 8 All Saint's Street, London, N1 9RL, UK. Tel: +44 (0)20 7272 7774, E-mail: bond@gn.apc.org

- Aims to put disability on the agenda for agencies working in the 'South'; becoming a focal point for access to information regarding disability issues which will enable members to keep up to date; and identifying and discussing current and pressing disability and development issues, identifying solutions and taking action in relation to these issues.

BUild, 12 Barford Crescent, Birmingham, B38 OBH, UK.
Tel: +44 (0)121 433 5417

- A network of families and individuals concerned to encourage greater awareness of people with learning disabilities in the churches and the Baptist denomination. It publishes some church materials on encouraging and assisting integration of people with disabilities into church life.

Causeway Prospects, PO Box 351, Reading, RG1 7AL, UK. Tel: +44 (0)118 950 8781, Fax: +44 (0)118 939 1683, E-mail: causeway@prospects.org.uk

- A Christian voluntary organisation which values and supports people with learning disabilities. It informs and encourages Christians in outreach and ministry to people with learning disabilities and supplies teaching and other materials.

Child to Child Trust, Institute of Education, 20 Bedford Way, London, WC1H OAL, UK. Tel: +44 (0)207 612 6646, Fax: +44 (0)20 7612 6645

- Peer education disability resource information and pack.

Child to Child Project, Nairobi, Kenya. Tel/Fax: +254 2 248602,
E-mail: child-to-child@africaonline.co.ke

Christian Blind Mission, Christoffel-Blindenmission e.V. Nibelungenstrasse 124: D-6140 Bensheim 4, West Germany

Christian Medical College Development of Paediatric Unit, Vellore 632004, India. Contact: Dr MC Matthew

- Regional medical advice for children with disabilities especially neurological.

Church Action on Disability (CHAD), 50 Scrutton Street, London, EC2A 4PH, UK. Tel: +44 (0)207 452 2085, Fax: +44 (0)20 7452 2001,
E-mail: mlpcfm@aol.com

- Education and awareness raising of disability in churches. Produce access audit, resource pack, study pack and youth pack. Quarterly magazine *All people.*

Communication Therapists International, c/o SD Hartley, Carlton Green Farm, Saxmundham, Suffolk, IP17 2QN, UK

- Support organisation for those working in communication disorders.

Community Based Rehabilitation Resource Centre (CBRRC), Centre for International Child Health (CICH), Institute of Child Health, University College, London, 30 Guilford Street, London, WC1N 1EH, UK. Tel: +44 (0)20 7242 9789, 24hr Answerphone: +44 (0)20 7404 1096, Fax: +44 (0)20 7474 2062,
E-mail: cich@ich.ucl.ac.uk, Website: http://cich.ich.ucl.ac.uk

- Encourage and conduct research, run courses and have a resource centre.

CBR Development and Training Centre, Jalan Adisucipto KM 7, Colomadu, Solo 57176, Central Java, Indonesia, Fax: +62 271 780976,
E-mail: cbr@slo.mega.net.id Contact: Prof Handojo

- Produce excellent resources on working with children with disabilities.
  1. *Early Detection of Disability for Children Under Five Years*
  2. *Detection of Childhood Disability Trainer's Manual*
  3. *Finding Out About CBR*
  4. *Finding Out About a Person and Her Problems*
  5. *Finding Out If Your Program Works: Evaluation and Monitoring*
  6. *Helping a Person to Move*
  7. *Helping a Person with Problems Breathing*
  8. *Helping a Person with Pain, Weakness or Stiffness*
  9. *Helping a Person Who Has Had a Stroke*
  10. *Helping Children Who Have Difficulty Eating and Drinking*
  11. *Helping Children Who Have Difficulty Talking and Communicating*

12 *Helping Children with Mental Handicap and Those with Behaviour Problems*
13 *Helping People with Severe Mental Illness*
14 *Helping People Who Have Epilepsy*
15 *Helping Prevent Disability*
16 *Simple Equipment to Help People with Disabilities*
17 *Special Activities to Help Children Grow*
18 *What is Disability?*
19 *Early Signs of Disability* (poster)
20 *Watch Us Grow* (poster)

Deaf Christian Network, PO Box 212, Doncaster, South Yorkshire, DN2 5XA, UK.
Tel: +44 (0)1302 369684 (Voice/Minicom), Fax: +44 (0)1302 739660

- Working with profoundly deaf people.

DPI International, 101–107 Evergreen, Winnipeg, Canada R3L 2T3,
Tel: +1 204 287 8010, Fax: +1 204 453 1364

- A worldwide membership organisation of national organisations of persons with disabilities. Its primary purpose is to be a voice for persons with disabilities internationally and to be a vehicle for self help for people with disabilities. It has information about disabled peoples rights/organisations in most countries.

Disabled Persons Unit, Department for Policy Co-ordination and Sustainable Development, UN, New York or on the Website:
http://www.un.org/ecosocdev/geninfo/dpi1647e.htm (see Resources)

Disability Awareness in Action, 11 Belgrave Road, London SW1V 1RB, UK.
Tel: +44 (0)20 7834 0477, Fax: +44 (0)20 7821 9539,
Text-phone: +44 (0)20 7821 9812, E-mail: 100726.236@compuserve.com.
Website: http://ourworld.compuserve/homepages/DAA_ORG

Disability Awareness and A Healing Ministry, The Revd Dr Nancy Lane, PhD,
PO Box 274, Lansing, NY 14882-0274, USA. Tel: +1 607 533 4083
(10:00am – 5:00pm only Eastern USA time), E-mail: nlane1@twcny.rr.com

- Working with women who have been abused or sexually exploited, including women with disabilities. Working with victims and survivors of clergy sexual abuse. Particular attention is given to the spiritual issues resulting from abuse and discovering (or recovering) a positive image of God and God's presence in suffering.

Disability, Pregnancy and Parenthood International, 45 Beech Street, 5th Floor,
London, EC2P 2LX, UK. E-mail: dppi@eotw.co.uk
Website: freespace.virgin.net/disabled.parents

- Information project and international journal.

Evangelical Alliance Disability Forum, 186 Kennington Park Road, London, SE11 4BT, UK. Tel: +44 (0)20 7207 2100, Fax: +44 (0)20 7207 2150

- Umbrella organisation for Christian disability organisations.

EENET Centre for Educational Needs, School of Education, University of Manchester, Oxford Road, Manchester, M13 9PL, UK. Tel: +44 (0)161 275 371, Fax: +44 (0)161 275 3548, E-mail: eenet@man.ac.uk,
Website: http://www.eenet.org.uk

- Information on inclusive education worldwide.

Handicap International, 14 Avenue Berthelot, 69007 Lyon, France.
Tel: +33 7869 7979, Fax: +33 7869 7994

- Expertise on leg prostheses.

Hard of Hearing Christian Fellowship, PO Box 91, Reading, RG1 5YR, UK.

Healthlink Worldwide (formerly AHRTAG), Disability Information Service, Farringdon Point, 29–35 Farringdon Road, London, EC1M 3JB, UK.
Tel: +44 (0)207 242 0606, Fax: +44 (0)207 242 0041,
E-mail: info@healthlink.org.uk, Website: http://www.healthlink.org.uk

- Advice on health and disability development in developing countries. Also has resource list of free newsletters.

Hearing International, Kyoiku Kohosha, Zaikyou Building, Sanbancho 30–2, Chiyoda-ku, Tokyo 102, Japan

- Newsletter networking centres for prevention of deafness and hearing impairment

Hesperian Foundation, PO Box 1692, Palo Alto, California 94302, USA

- Produces *Disabled Village Children* and newsletter *Sierra Madre Newsletter*.

Indian Institute of Cerebral Palsy, Spastic Society of Eastern India, P-35/1 Tarratola Road, Calcutta 700 088, India.

- Excellent training materials in working with children with disabilities.

Intermediate Technology Publications, Unit 25, Longmead, Shaftesbury, Dorset, SP7 8PL, UK. Also have a book shop at 103–105 Southampton Row, London

International Agency for the Prevention of Blindness (IAPB), c/o Sightsavers, PO Box 191, Haywards Heath, West Sussex, RH16 4YF, UK.

International Care for Eye Health, Institute of Opthamology, 27–29 Cayton Street, London, EC1V 9EJ, UK

- Free newsletter.

International Centre for the Advancement of Community Based Rehabilitation (ICACBR), Queens University, Kingston, Ontario, K7L 3NG, Canada.
Tel: +1 613 545 6881, Fax: +1 613 545 6882, E-mail: icacbr@post.queensu.ca

- CBR Update newsletter for the advancement of community-based rehabilitation.

International Society for Prosthetics and Orthotics, Borgervaenget 5, 2100 Copenhagen 0, Denmark.

Inclusion International (formerly International League of Societies of Persons with Mental Handicap – ILSMH), Galleries de la Toisen d'Or, 29, Chassee d'Ixelles, #393132 B-1050 Brussels, Belgium. Secretariat: 248 Ave Louise, bte. 17 Brussels, Belgium B1050. Tel: +32 2647 6180, Fax: +32 2 647 2969

Initiatives for Deaf Education in the Third World, 9 Church Walk, Much Wenlock, Shropshire TF13 6EN, UK. Tel: +44 (0)1952 728 057, Fax: +44 (0)1952 728 057

JAF (Joni Erickson Tada) Ministries, PO Box 3333, Agoura Hill, Ca 91301, USA

L'Arche International, BP35, 60350 Trosly-Breuil, France. Tel: +33 44 859480. Fax: +33 44 859267

- Catholic communities of people with learning difficulties and non-disabled living together in Christian community.

Leprosy Mission International, 80 Windmill Road, Brentford, Middlesex, TW8 0QH, UK. E-mail: june@tlmint.org

Liverpool School of Tropical Medicine Hearing Impairment Research Group, Pembroke Place, Liverpool, L3 5QA, UK

Malaysian CARE, Lot 389, 8.8km Jalan Ulu Kelang, 68000 Ampang, Selangor Darul Ehsan, Malaysia. Tel: +60 3 4568715, Fax: +60 3 4514044,
E-mail: mcare@po.jaring.my

- Produce newsletter *Partners*.

Motivation, Brockley Academy, Brockley Lane, Backwell, Bristol, BS19 3AQ, UK.
Tel: +44 (0)1275 464012, Fax: +44 (0)1275 464019,
E-mail: motivation@motivation.org.uk, Website: http://www,motivation.org.uk

- Provision of wheelchairs and training in use, also incontinence care/aids etc.

Oxfam UK and Ireland, 274 Banbury Road, Oxford, OX2 7DZ, UK.
Tel: +44 (0)1865 313925, Fax: +44 (0)1865 313925, E-mail: publish@oxfam.org.uk

People Potential, Plum Cottage, Hattingley Road, Medstead, Alton, Hampshire, GU34 5NQ, UK. Tel: +44 (0)1420 563741

- Courses in creativity, appropriate disability design, community-based work.

Radda Barnen (Swedish Save the Children), SE-107 88 Stockholm, Sweden.
Tel: +46 8 698 90 00, Fax: +46 8 698 90 14. Publications E-mail: rbpublishing@rb.se
Website: http://www.rb.se/tools

Rehabilitation International, 25 East 21st Street, New York, NY 10010, USA.
Tel: +1 212 420 1500, Fax: +1 212 505 0871

South Africa Federation of the Disabled (SAFOD), PO Box 2247, Bulawayo, Zimbabwe.

Special Education Unit, Ministry of Education, PO Box 47, Maseru, Lesotho

- Training video on preparing teachers for inclusive education available from EEMET or SCF UK.

SPRED, Special Religious Education Department (RC Church), c/o Brothers of Charity Services, Lissieux Hall, Whittle-le-Woods, Chorley, Lancashire, PR6 7DX, UK. Tel: +44 (0)1257 266 311

- Looks at spiritual needs of people with learning difficulties and provides suitable study and worship material.

TALMilep, 234 Blythe Road, London, W14 OHJ, UK. Tel: +44 (0)207 602 6925, Fax: +44 (0)207 371 1621, E-mail: mtamplin@ilep.org.uk
Website: http://www.oneworld.org/ilep. Also see infolep@antenna.nl

- Made up of representatives of International Leprosy Organisation member associations with particular interest and expertise related to teaching and training.

Teaching Aids At Low Cost, PO Box 49, St Albans, Herts, AL1 5TX, UK.
Tel: +44 (0)1727 853869, Fax: +44 (0)1727 846852, E-mail: talcuk@btinternet.com

- As well as providing many of the above books at low cost they also produce slides (such as a 'Community Based Rehabilitation' set) and other accessories. Catalogue available on request.

Through the Looking Glass, National Centre for Parents with Disabilities, 2198 Sixth Street, Suite 100, Berkeley, Ca 94710-2204, USA. Tel: +1 510 848 1112, Fax: +1 510 848 4445, E-mail: TLG@lookingglass.org, Website: www.lookingglass.org

- Community organisation pioneering clinical and supportive services, training and research serving families in which one or more members (whether parent or child) has a disability or medical issue.

Through the Roof, PO Box 178, Cobham, Surrey, KT11 1YN, UK.
Tel/Fax: +44 (0)1932 866333, E-mail: info@throughtheroof.org,
Website: www.jafministries.com/throughthe roof

- The disability outreach of Joni Erickson Tada. Produces a series of one page *Roofbreaker Guides* about including people with different types of disabilities in the church.

Torch Trust for the Blind, Torch House, Hallaton, Market Harborough, Leicestershire, LE16 8UJ, UK. Tel: +44 (0)1858 555301, Fax: +44 (0)1858 555371

- Christian resources for blind and visually impaired people.

Uganda National Institute Special Education, PO Box 6478, Kampala, Uganda

- Pan African advice on disability and special needs including the *African Journal of Special Needs Education.*

United Nations Secretariat, Division for Social Policy and Development, Room DC2-1342, New York, NY 10017, USA. Tel: +1 212 963 3897/6765, Fax: +1 212 963 3062

- *Disabled Persons Bulletin*, published three times a year in English, French and Spanish.

UN Special Rapporteur, PO Box 16363, S-103 26 Stockholm, Sweden. Tel: +46 8 453 4022, Fax: +46 8 24 88 47, E-mail: un-spec.rapp@stockholm.mail.telia.com

UNESCO, UN Educational, Scientific and Cultural Organisation, 7 Place de Fontenoy, 5-75007 Paris, France. Tel: +33 1 45 68 1000, Fax: +33 1 40 65 9405

- Guide for special education and resource person for special education.

UNICEF, UNICEF House H2F, 3 United Nations Plaza, New York, NY 10017, USA.

World Blind Union, 58 Bosquet, 75007 Paris, France. Tel: +33 1 45 55 6754, Fax: +33 1 45 56 0740,
and 224 Great Portland Street, London, W1N 6AA. Tel: +44 (0)20 7388 1266

- Global organisation of people with visual impairment.

World Health Organisation Disabled Persons Unit, WHO 1211, Geneva 27, Switzerland. Website: www.who.ch Representative: Enrico Pupulin

World Institute on Disability, 510 16th Street, Oakland, CA 94612-1502, USA. Tel: +1 510 763 4100, Fax: +1 510 763 4109, E-mail: cathy@wid.org

- A disability-led organisation that works extensively in independent living. It provides training and technical assistance to disability groups in developing countries in organisational development, leadership training, advocacy and public education campaigns; working with government, media and corporations.

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E-mail: roots@tearfund.org

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