

Family Action for Inclusion in Education



“ We have realised over the past few years that too much reliance is placed on the memory of members to recall the history of the organisation, as well as the incredible amount of work and countless activities that we have performed. We have often lamented that we need a written record to be handed down to future generations.

This particular involvement with the EENET project further highlights the importance not only to QPPD, but to all parents... we now know that a written history is imperative. We would suggest that other parent organisations do the same, as it will become a mammoth task later. ”

*Queensland Parents of People with a Disability (QPPD)
Australia*

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- QPPD, Australia
- APASENTH, UK

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Introduction

Who is this guide for?

This guide has been written primarily for family members who may feel isolated and want to form a support group or advocacy organisation. It draws on the inspirational stories of seven advocacy organisations in southern Africa, South Asia, Europe and Australia in their various stages of development. It aims to recognise and celebrate the contribution made by parents, family and community members who have campaigned for the inclusion of disabled children in education. In many countries this has led to the transformation of individual schools and education systems. We hope that by reading this guide you will feel less alone and more confident about what is possible. Our intention is to inspire you, not to give instructions or provide a blueprint.

What does it cover?

Family involvement in education

Inclusion starts in the family home. Although this guide mostly refers to the role parents have played in promoting inclusion, we acknowledge that the role of the extended family is extremely important and should be recognised. Greater family and community involvement in formal education is essential to the inclusion process.

The experience of discrimination

Poverty, gender, ethnicity and disability are some of the major issues of difference, which often lead to discrimination and cause large numbers of children to be excluded from formal education. This is particularly true of

countries in the South, where education is not compulsory, and school fees usually have to be paid.

Initially we set out to find stories of a range of parent groups representing all aspects of difference and discrimination. However, we were only able to find examples of parents campaigning for their disabled children. The advocacy role played by the (non-disabled) parents of disabled children seems to be unique. It is quite different from the role that parents of children experiencing other forms of discrimination may play.

Disabled children tend to be born to non-disabled parents. Living with a disability is therefore not an experience which the parents share with their children. Parents who are poor, or members of a minority ethnic group, however, experience the same sort of discrimination as their children. Similarly, girls and their mothers are both likely to experience gender discrimination. Many of the stories we gathered describe experiences of multiple forms of discrimination, where disabled girls and boys are also poor and belong to a low social caste or an ethnic group.

Using the guide

This guide is divided into **five main sections:**

- First there is a section of background information. This includes information about EENET and its definition of inclusive education; a history of this project; some notes on terminology; and profiles of the organisations that have contributed to the project.
- *Part 1 – Building an organisation* looks at the way organisations have been started, and how the members have been empowered, despite the struggle, in some cases, for day-to-day survival.
- *Part 2 – Reaching out* shows how it is possible to involve members of the community in promoting inclusive education, and how some groups have become involved in raising awareness of wider issues of marginalisation.
- *Part 3 – Looking to the future* provides ideas and inspiration for further developing the work of support groups and organisations.
- *Part 4 – Resource materials* contains information from relevant sections of international instruments and documentation, such as the UN Convention on the Rights of the Child (UNCRC). It also contains a list of useful publications and videos, and contact details for some key organisations.

Part 1, Part 2 and Part 3 are divided into shorter sections, at the end of which you will find some suggested **discussion questions** to help you and your organisation think through some of the issues raised and consider how they apply in your specific context. We have also provided spaces in which you can make notes or write in your own questions for discussion.

Throughout the booklet there are **quotations from the advocacy group stories**. These quotations provide the reader with valuable insights into the activities, thoughts and feelings of parents involved in fighting for the inclusion of their disabled children. They have been drawn from a variety of sources: written material, interviews, e-mails, conversations. In some cases, the quotations are credited to a particular individual, in other cases they appear in a section of text devoted to a named organisation.

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EENET

The Enabling Education Network

EENET is an information-sharing network which supports the inclusion of marginalised groups worldwide.

EENET's office is based at The University of Manchester, in the School of Education, but is independently funded by European NGOs and has an international steering group.

EENET was established in April 1997 in response to the information needs of inclusive education practitioners, particularly in Africa and Asia. EENET promotes easy-to-read and relevant discussion documents and training materials. *Enabling Education*, EENET's newsletter, helps to promote South–South and South–North networking by stimulating discussions and sharing stories. Here is a summary of the philosophy behind the establishment of EENET.

EENET

- believes in the equal rights and dignity of all children
- prioritises the needs of countries which have limited access to basic information and financial resources
- recognises that education is much broader than schooling
- acknowledges diversity across cultures and believes that inclusive education should respond to this diversity

- seeks to develop partnerships in all parts of the world.

In conducting its work, EENET

- adheres to the principles of the Salamanca Statement (see p.99)
- believes that access to education is a fundamental right
- recognises the intrinsic value of indigenous forms of education.

EENET is committed to

- encouraging the effective participation of key stakeholders in education
- engaging with the difficulties caused by the global imbalance of power
- encouraging a critical and discerning response to all information and materials circulated.

Definition of inclusive education

Inclusive education

- acknowledges that all children can learn
- acknowledges and respects differences in children: age, gender, ethnicity, language, disability, health status, etc
- enables education structures, systems and methodologies to meet the needs of all children
- is part of a wider strategy to promote an inclusive society
- is a dynamic process which is constantly evolving
- need not be restricted by large class sizes or a shortage of material resources.

International Disability and Development Consortium (IDDC) seminar on inclusive education, Agra, India, 1998

Background to the Family Involvement Project

As we see in this guide, practitioners can learn so much from sharing stories of their own experiences – stories of what works, and what does not work. This is central to EENET's philosophy. The flow of information has too often been from North to South and it is EENET's mission to promote South–South and South–North information flows. The collection, publication and celebration of stories is central to the redressing of this imbalance.

How the stories were collected

A set of key questions was drawn up with a series of prompts under each question. It was suggested that a facilitator could carry out an interview with the parent group, and with young disabled people where possible. Guidance notes for facilitators were prepared and circulated. The pro forma of questions was meant as a guide for an interview, but it was made clear that it could be changed to suit the situation. Parent groups were asked to tape-record the interview, where possible, and to send a transcript and accompanying notes if the tape recording was not very clear. The pro forma was piloted early in 1999 in Lesotho and South Africa, and adaptations were made based on this experience.

The second stage was the selection of groups and the collection of stories. Introductory letters were sent to parent groups and to practitioners who work closely with parents, primarily in Africa, Asia and South and Central America, but also in Europe and Australia. The selection process took the following issues into account:

- representation from each major region in the world

- a balance of local and national examples
- experience of campaigning for inclusive education
- active participation in the education process
- a variety of educational responses – not only school-based experience
- most of the stories should come from the countries of the South.

In early 2000 the transcribed stories were sent to the parent groups for checking. In May 2000 a meeting was held in Manchester of critical friends who had read the stories and were prepared to provide us with feedback. They included parents, disabled people and university students. The group was supportive of the project, but critical of the academic style and the lack of authentic voices in the stories. The stories were re-edited to address this criticism. In July 2000 EENET's steering group decided that it would be more appropriate to use the information contained in the stories to produce a user-friendly and practical handbook for practitioners. The stories were made available on EENET's website, and EENET's co-ordinator began to develop the current publication with support from EENET's steering group.

This piece of research was funded by Save the Children Sweden and carried out by a consultant who worked closely with EENET.

Story guide

Summary of key questions

- Please tell us about your group or organisation.
- Can you tell us about the national or local situation of education?
- What is your parent group or organisation's role in relation to education?
- What difficulties do you face?
- What are your group's strengths?
- What strategies have you used to overcome difficulties?
- What are your group's future plans?
- What advice does your group have for other parent groups?

Terminology

When compiling a publication like this it is always difficult to find words and phrases that will mean the same to all readers and which will not have negative connotations.

Many different words are used to describe disabled children and adults, particularly those who have learning difficulties. It is important that we continually reflect upon the words we use. We should raise questions about all terminology that labels people as being different from others; we should question the meaning, and the effect on the people we are describing.

The first set of words listed below are no longer considered acceptable by people with learning difficulties in many English-speaking Northern countries:

Mental	disability	Mentally	disabled
	handicap		handicapped
	retardation		retarded

Many of the parent groups who have contributed to the stories reflected in this publication continue to use the above words. In consultation with these groups, however, we decided to edit the stories in order to be consistent about the language we use in this publication. We have therefore adopted the use of the term 'learning difficulties'.

The following terms are also commonly used:

Learning	disability	Intellectual	impairment	Intellectually disabled
	disabled		disability	impaired

Direct quotes have not been changed, however, nor have the names of organisations such as the Lesotho Society of Mentally Handicapped Persons.

Profiles of contributing organisations

Asian Parents' Association for Special Educational Needs in Tower Hamlets (APASENTH), London, UK



APASENTH was formed as a group in 1984 by the parents and carers at a special school. It provides a range of services to over 300 Bangladeshi families who care for children and adults with disabilities and learning difficulties. Advice and support is available in Sylheti and Bengali on a daily basis. APASENTH meets the particular needs of the minority ethnic group of Bangladeshi parents whose children are disabled.

Community Based Rehabilitation Service (CBRS), Nepal



CBRS, a community-based organisation, has been working for, and with, disabled children and their families since 1995. CBRS clients have physical disabilities and/or learning difficulties, and CBRS networks with, and refers to and from, other local organisations working with other types of impairment. CBRS works closely with the families of disabled children in all activities, such as community awareness, home visits, and parent groups for self-help and advocacy. The overall aim of CBRS is to improve the quality of life of disabled people, both now and in the future.

Disabled Children's Action Group (DICAG), South Africa

DICAG was established in 1993 by the parents of disabled children. “*One of our main aims is to empower ourselves to educate our children in an inclusive environment.*” DICAG was initially affiliated to Disabled People

South Africa (DPSA), the national disabled people's umbrella organisation, but is now an independent organisation.

DICAG is a campaigning organisation, which helps to raise the level of awareness of disability and challenges stereotypes and perceptions of disabled people in South Africa. DICAG aims to ensure equal opportunities for disabled children, especially in education.

Lesotho Society of Mentally Handicapped Persons (LSMHP), Lesotho

LSMHP was established in November 1992 by parents of children with learning difficulties; later parents of children with other disabilities joined the organisation. It has representation throughout Lesotho. Its mission is to protect the rights of people with learning difficulties, and children with other disabilities, so that they may realise their full potential and achieve full rights in society. This is achieved through awareness-raising, lobbying and advocating, and providing training to families and the community.

Queensland Parents for People with a Disability (QPPD), Australia

QPPD is a statewide advocacy organisation which was established in 1981 and is managed by families. QPPD has a Brisbane-based office which has three full-time and one part-time staff, but families are at the heart of the organisation's work.

Social Assistance and Rehabilitation for the Physically Vulnerable (SARPV), Bangladesh



SARPV is a disabled people's organisation which was set up in 1988. It was in 1999 that they began to focus their attention on parents. SARPV has a range of programmes: community-based rehabilitation (CBR); research and documentation; awareness and motivation; advocacy, lobbying and networking; education; skills training and income-generation; and a post-disaster programme.

Speranta, Timisoara, Romania

Speranta, which means ‘Hope’, is a non-governmental, non-profit organisation, established by parents in 1990. Its main goal is to improve the quality of life for people with learning difficulties. Its philosophy is inclusion, based on a belief in human rights and equality. The Special Educational Centre ‘Speranta’ is an independent organisation in Timisoara, established in response to the needs of parents.

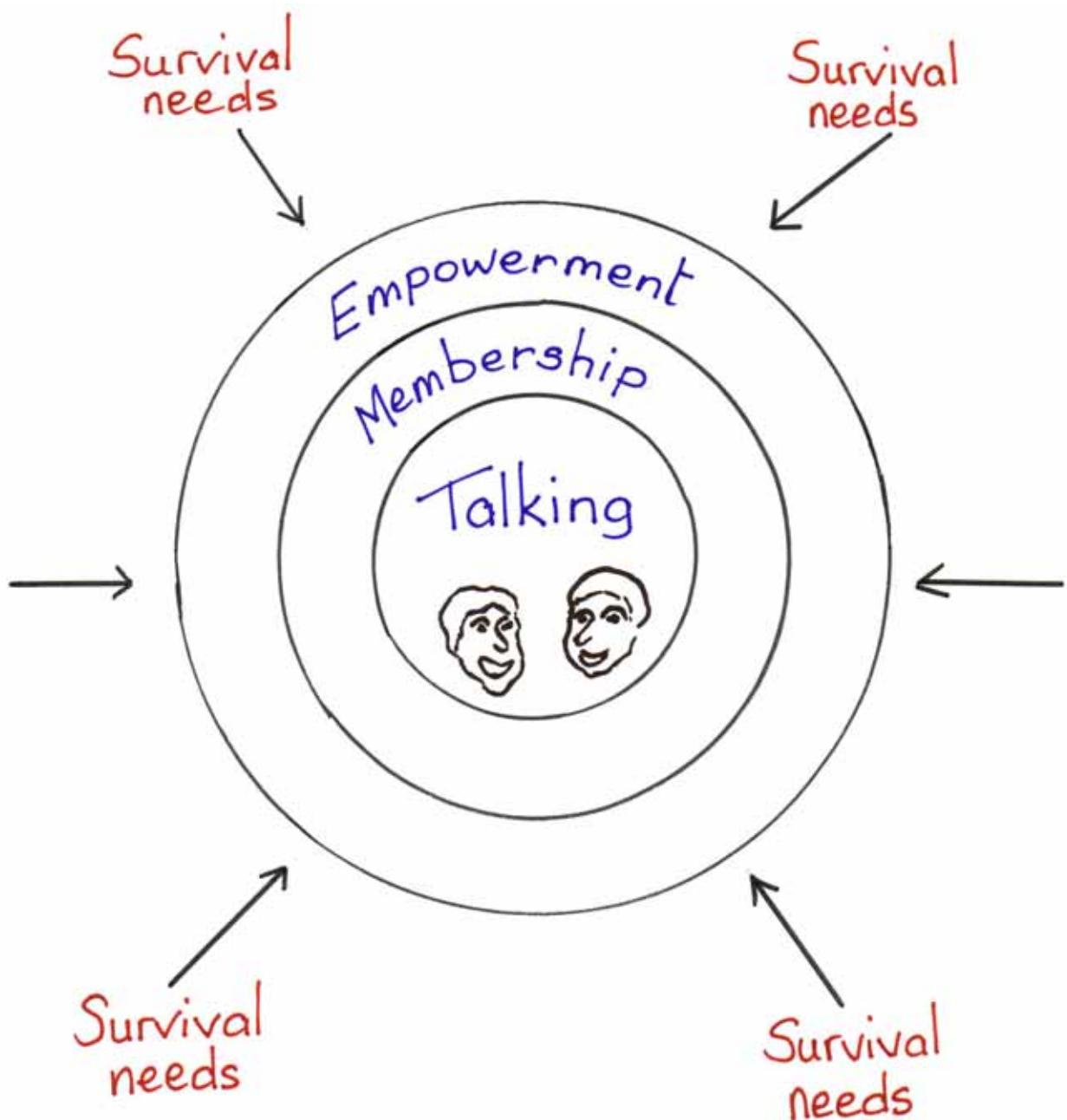


TREBUIE!, Bucharest, Romania

TREBUIE! was founded in Bucharest in 1993 by a group of parents with children who had learning difficulties, together with some professionals specialising in this field. TREBUIE! means ‘We ought to’. Its main purpose is to ensure a “dignified life in society” for children and adults with learning difficulties, in line with the UN Conventions on Human Rights and the Rights of the Child.

Part 1

Building an Organisation



In 'Talking' you will hear from parents in Bangladesh and Australia about the early stages of the development of their advocacy organisations – and in particular, about their need to talk and share stories.

Talking

Coming together and meeting other parents of disabled children has given us courage! We used to hide our disabled children away, but now we have the confidence to bring them outside our homes.

Parent,
LSMHP, Lesotho

The greatest need in the early stages of the formation of an advocacy organisation, or a family support group, is to talk. Talking and listening will continue to be important as new members join. Joining a mature group, where parents have gained lots of confidence and experience, is very different from starting a group for the first time. Here we have two examples of parents meeting for the first time in very different circumstances: in Bangladesh in 1999; and in Queensland, Australia in 1980. Despite the contrast in material circumstances between the two countries, the emotions expressed are very similar.

Mohammadpur Thana, Bangladesh

A group of parents met for the first time in Mohammadpur Thana, Bangladesh, in 1999, and kept a record of the stories that were told. They were encouraged to meet by a local non-governmental organisation run by disabled people, called SARPV (Social Assistance and Rehabilitation for the Physically Vulnerable). There are many other well-established organisations in Bangladesh which have been responsible for developing services for their children since the 1980s, but here we listen to parents talking to each other about their children for the first time.

The idea of coming together was to develop a forum for parents of disabled children to promote inclusion from the very early stages of their lives, not specifically about including children in education. SARPV e-mailed the minutes of this meeting to EENET in response to the call for stories about family involvement in inclusive education. This was a unique opportunity to capture the parents' hopes and fears, and their need to talk to others with similar experiences. Since the meeting in 1999, the parents have been responsible for organising their own meetings, initially in each other's homes.

Although the first meeting was called to talk about all aspects of inclusion, some of the parents mention their children's education in passing. Mamun, for example, has had some basic education and his mother is supportive and concerned about his future:

My son's name is Mamun and he is 14 years old. He became physically disabled after he was ill with a high fever.
Mamun went to school up to class four. He is quite skilled in repairing electronic equipment. I will help him with this.
I plan to buy him a wheelchair to aid his mobility.

Her last comments, however, indicate that Mamun does not feel included in his own community:

The rest of the family do not neglect or mistreat him at all, but he does not like to go out of the house.

Some parents experience considerable isolation and feel unable to take their children out of the house:

We have three children. Our eldest son, Kamruzzaman, is 18 years old. He is mentally retarded and suffers from epilepsy. I never take him out or allow him to take part in any social gathering because I am afraid he may have a fit at any time. Once I did take him and he had a fit. It was awful. Every guest at the function crowded round and blamed me for being greedy and bringing him because I

wanted to eat the good food at the party! I burst into tears and left. For the last ten years since this happened, I have never taken him out of the house. Kamruzzaman stays at home alone. There is no way I can take him with me.

Kamruzzaman's experience of school has not been a positive one either:

Nor does he go to school. That, too, was a bad experience. The teachers told me that Kamruzzaman upset them and was disturbing to the other children. His schooling just stopped. I tried to get treatment for him and spent a lot of money but it was no good, there was no improvement.

Sumy's mother has also experienced feelings of embarrassment and isolation:

My daughter's name is Sumy. She is 18 years old and has been physically disabled from birth. She suffers pain in every joint in her body. She can walk by herself but she is not able to keep her balance. The doctors say there is no treatment for her condition. She should have physiotherapy on a regular basis. Now that Sumy is grown up I think she should do the exercises on her own, but she does not do them...

I too feel very embarrassed about taking Sumy to social functions. Some people look her up and down in such an awful way that I don't know what to do. I feel like hiding myself and my daughter! Now I am planning to give her some skills training and to give her some property in her own name. I will also try to find a gentle bridegroom, to arrange a marriage for my daughter.

For some there were feelings of sadness initially:

I have four children. Tomal is my second son. When he was six months old he fell ill. Since that time he has been mentally and physically disabled. His whole body is totally paralysed. I used to think, "Why has this happened to me? Is it a punishment for my sins?". It was hard for all our relatives. Only after 16 years have I realised there is no point to these questions. It helped when a well-wisher pointed out to me that it was not my responsibility to find out why this had happened. That helped me to change my thinking. My pain and sorrow left me. Now I feel really happy. I think my son is very innocent and I feel that in loving my son I am serving my God. Like every other parent who has spoken we also spent a lot of money for treatment for our son.

And some of the parents expressed their hopes and dreams for their children's future:

We were very worried and fearful for his future when he was born and very pessimistic. Now it is just the opposite! We are confident that one day he will be able to work to improve the lot of other vulnerable human beings.

Our son, Zeebon, is 18 years old, and has been physically disabled from birth. His disabilities do not stop him from leading a normal life. He has taken his HSC examination this year and we are very hopeful about his future. We are sure that one day he will establish himself in society with honour and prestige.

Our daughter, Nashit, is four years old. She has trouble with walking and she also has fits which can happen at any

time. Doctors have advised us to let her have an operation on her leg but her grandfather did not like the idea. He thought the operation might not be successful, so we did not go ahead with it. She does have treatment for her fits and takes her medicine regularly. We have tried every kind of treatment. But we remain hopeful. Nashit is very intelligent and we believe that she will establish her place in society like any other non-disabled child.

The meeting was successful in enabling parents to share their personal stories. The stories reflect many common issues such as the large amounts of money often spent on medical treatment, the feelings of shame, and the hostile attitudes which some children and their parents have experienced. Many of the parents told of their initial despair and ongoing isolation. In several cases the parents' own attitudes to their experience have been transformed. They are now hopeful and optimistic about the future, having come to terms with disability.

Everyone agreed that they must continue to meet to discuss ways of helping not only members' children, but also other poor and vulnerable disabled children. They decided to meet on the last Friday of each month. Another decision was that the meetings should be in each member's house in turn and that the aim should be to discuss problems and look for solutions.

We hope that, through these regular meetings, the group will decide to lobby both government and non-governmental organisations to further the development of their children. In this and other ways the group will raise awareness in society of the rights of, and opportunities for, their children.

SARPV Programme Officer

Queensland, Australia

Parents first came together in Queensland, Australia, to form the Queensland Parents for People with a Disability (QPPD) in 1980. Although Australia is a well-resourced country and communication is much easier than in Bangladesh, the parents also felt isolated and needed to share their stories. Their original stories are not well documented because they did not keep detailed records, much to their regret. However, in response to EENET's call for stories, they have pieced together their experience.

It has been a very positive experience working with some of the key parents to try to capture something of the story of QPPD's Inclusive Education Network.

David Bowling,
Advocacy Development Worker

As part of the International Year of Persons with Disability (IYPD), a national women's group organised an Australian Women's Conference in 1980. A few women from Queensland followed this up by holding a workshop which provided the first opportunity for about 150 parents from all over Queensland to come together. They met for three days to talk about their family situations and the fact that having a child with disability made a difference to the family. There were a few men at the conference, but the majority of parents were women, and it was mothers who probably had the main caring role.

The conference was very emotional. The unique thing was that parents spoke to parents. People who spoke were very angry about many issues. It was felt that this energy needed to be channelled constructively. At the end of the conference there was unanimous agreement to set up an organisation in Queensland to lobby around issues that were relevant to their children and families.

It was a reaction against the feeling of being powerless to influence service provision and government decisions.

QPPD member

The strengths of this advocacy group are that there is great clarity and passion about what people want; great courage, commitment and mutual support; intense interest in the 'journeys' of individual families; and a

willingness and an ability to work both at a systems level, and as a lobbying group.

There was always someone with a new story – often something very exciting that they had achieved or that their child had achieved beyond expectation...

The stories are probably where I gained a lot of strength and what gave the group a lot of strength.

QPPD member



Questions for discussion



- How can family members be helped to come to terms with disability and challenge the discrimination they face in society?
- How can family members celebrate their positive experiences?
- What role can the media play in changing attitudes and discrimination?
- Would it help to meet with other groups who have similar experiences of social stigma and discrimination? If so, how?



Notes

In ‘Membership’ we hear about how new members are recruited, different types of membership, and the way organisations change as they become more inclusive.

M_{ember}ship

Recruiting new members and spreading the word

It is interesting that on three different continents, in Bangladesh, South Africa and Australia, parents felt the need to go from door-to-door, recruiting other parents to join their organisations in the very early stages of the organisations’ development.

In Mohammadpur Thana, Bangladesh...

In Bangladesh the decision to do door-to-door visiting was made at the first meeting:

We also agreed that we should all take part in going from door to door visiting poor disabled people to get them involved.

In South Africa...

The same commitment to recruiting parents to join the organisation was reported from the Disabled Children’s Action Group (DICAG) in South Africa:

We found that visiting families door-to-door and talking to parents on a one-to-one basis was the only way to gain

their trust, engage their interest and mobilise their commitment.

In Queensland, Australia...

We succeeded in getting a small amount of money from some government departments to enable two parents to travel around the state for three weeks to publicise the organisation. They stopped off at different places on the coast and walked around with big red QPPD badges. They stopped people to ask them, "Do you know of any people who have children with a disability in this town?". They talked on local radio, visited local schools and hospitals, wherever we thought disabled children might be, and wandered around looking for them. They tried to include any family they came across with any disabled child.

There was no money to start with and all the planning was done in the homes of people on the committee. There were only a small number of members in Brisbane, the capital of Queensland; the others lived all around the state.

It is important to keep re-visiting the vision and bringing new parents along the road with you.

Who are the members?

There are many different types of family-based advocacy organisations. Each has its own ideas about who should be a member. Some organisations do very little advocacy work and instead focus on providing services for children with a particular impairment. In some countries, however, there has been a movement away from service provision towards empowerment. As organisations increasingly include persons with learning difficulties as full members, they naturally focus more on empowering those members.

DI CAG is governed by, for, and with parents of children with disabilities.

South Africa

Some groups have an open membership, where parents of children with all types of impairment are welcome. Increasingly advocacy organisations encourage disabled young people themselves to become members – they are sometimes called ‘self-advocates’. Some groups welcome ‘supporting members’. These may be professionals or friends who wish to support the organisation. Other groups, however, have preferred to restrict their membership to parents of children with a particular impairment. Here are some examples of different types of membership and organisational goals:

Queensland, Australia

“From the beginning QPPD was inclusive of families from all backgrounds and all disabilities – because every type of disability was represented at the original workshop and no one wanted to be left out.”

QPPD describes itself as an advocacy organisation. Its members advocate on behalf of people with disabilities by:

- collecting and sharing information about what is happening in the lives of people with disabilities and their families around the state
- monitoring legislation, policies and practices which exclude people with disabilities and prevent families from having decent lives
- speaking out and writing about systems which maintain abuse and segregation, promoting the vision of supporting and safeguarding community living
- influencing political, bureaucratic, social and service systems that affect opportunities for children and adults with disabilities.

Lesotho

All people with learning difficulties and their families can become members of LSMHP. Since 1994 membership has been extended to include parents of children with other disabilities. Supporting membership is available to professionals in the field of disability and also to other people who are willing to work for the society's objectives and goals.

"Our main focus is on the empowerment of families and disabled people themselves – to cope better with daily living and to advocate for inclusive services. Education has been a priority from the very beginning. A key article in our constitution states that society exists to support our children's inclusion in schools, in employment, and in the community as a whole."

Romania

Under the communist regime it was illegal to set up any organisation for children or adults with learning difficulties. Only two disability organisations were supported by the government – these were for blind and deaf people.

It was only in April 1990, after the fall of the communist state, that a group of 25 parents came together in Timisoara. They set up a committee and organised an open meeting for parents of children with learning difficulties. Forty parents attended and shared their worries about their children and the future. They subsequently set up Speranta, an organisation through which they can fight together for a better life for their children.

"Only parents of children with a registered disability of mental handicap are eligible to join Speranta. We decided against including adults with mental illness who wanted to join the organisation. We hold weekly meetings in the afternoons after work so that both mothers and fathers can come."

England

"We feel that our children need a far greater level of help and attention because of the combination of our cultural background and the children's disabilities."

The Asian Parents' Association for Special Educational Needs in Tower Hamlets (APASENTH) was initially set up in 1984 by parents whose children attended a particular special school in Tower Hamlets, London. Now it serves the needs of all children with learning disabilities in the community. Some of the parents oppose special schooling because they fear the stigma, and they believe that their children have a better chance of improving both socially and academically in a mainstream setting. Others, however, feel that their children are safer in special schools.

"In 1984 I became very dissatisfied with my son's lack of progress. He could not speak or dress himself. I decided to get together with other parents with disabled children at the same local special school. So the origins of the association had education as its core focus. We meet weekly to share experiences, give each other advice and support, and promote our children's learning and happiness".

APASENTH provides information, advice, advocacy, counselling and other services to Asian parents and carers, and, in particular, to Bangladeshi children and young people with learning difficulties. APASENTH's membership, and the staff it employs, is primarily of Bangladeshi origin.



Questions for discussion



- Have you tried going from door-to-door to recruit members? What happened?
- What differences are there likely to be between the membership of advocacy organisations in rural and urban areas in your country?
- Is it helpful to have organisations that focus on a single impairment, eg deafness or a rare inherited condition, or is it better that parents of all disabled children organise together?
- What are the advantages and disadvantages of the parents of minority ethnic groups, such as the Bangladeshi community in London, organising separately?
- At what stage should advocacy groups invite parents campaigning against other issues of discrimination to join their campaign for inclusive education?



Notes

In ‘Survival’ we hear from South Africa and Romania, where family members set up their own ‘special centres’ because of the lack of government services. This enabled the mothers – the sole providers for their families – to go out to work and meet the basic needs of all the family members.

Survival

The primary concern of all parents is to ensure the survival and development of their children. In countries where many babies die before their first birthday this concern is even greater. Bringing up children in poor communities involves a day-to-day struggle for survival. Basic needs for clean water, food, shelter and healthcare have to be met and education is often considered a luxury.

Article 6 of the UN Convention on the Rights of the Child (UNCRC) states that every child has the inherent right to life, and the state has an obligation to ensure the child’s survival and development.¹

Poverty is closely linked to disability. Marginalised groups are more likely to be excluded from basic healthcare facilities. This, in turn, threatens their survival. Disabled people often face multiple forms of discrimination: they may also be economically poor, refugees, or belong to a minority ethnic group.

The parents of disabled children are often so preoccupied with the day-to-day struggle for survival that they simply do not have time to organise themselves and campaign for their children’s rights. Some parent groups prefer to focus on meeting their immediate needs and do not see it as their role to lobby for change.

We experience an ongoing tension between our dual approaches of advocacy and development... a continuous struggle against sliding into service provision because of the pressure of needs at grass-roots level.

DI CAG, South Africa

¹ See p.97 for information on obtaining copies of the UN CRC. Also see Jones (2001) *Disabled Children’s Rights – a practical guide*, Save the Children Sweden (details on p.102)

This tension between meeting the basic needs of disabled children and their families, and campaigning for the provision of, and access to, health, education and welfare services by the government is present in most parent organisations. The danger of providing services is that the impact will be limited to a small number of children and government policy is unlikely to be challenged. However, it is very hard to overlook the immediate need for food, care and basic education in poor communities. The following examples from South Africa and Romania illustrate ways in which parents have supported each other by developing services to meet their needs.

KwaZulu-Natal, South Africa

South Africa has adopted one of the most progressive constitutions in the world since the end of apartheid in 1994, when the first democratic elections took place. Although it is rich in gold and diamonds, there continues to be inequality in wealth and opportunities in its population of over 43 million. Big differences exist, in particular, between ethnic groups, and between rural and urban areas.

In the province of KwaZulu-Natal, in the early 1990s, a group of parents started with nothing. Their disabled children were excluded from the local school, as the education authority was hostile to the idea of inclusion. The advocacy group consisted of unemployed women, most of whom were the sole carers of their children and had little or no education. They agreed that one or two of them would look after the children, leaving the others free to look for work. Each parent would send something with their child – half a cabbage, a carrot, a potato, an apple – whatever they could manage. With these ingredients they cooked soup.

They organised a rota for caring for their children. One volunteered to cook; one became a teacher; others looked for work. Parents who managed to find work began to contribute a little to those who cared for the children. One worker began to buy bread for the children. A social worker heard about the group and came to see what they were doing. She was successful in negotiating for an allowance to be paid to those who stayed to care for the children. That was the start of the early childhood development centre.

Timisoara, Romania

The Romanian parents' organisation, Speranta, was started in 1990 by a small group of 40 parents. The first priority was to create a base for children with severe learning difficulties, aged three years and upwards,

because these children were rejected by everyone – even the special schools. They stayed at home all the time. It is very difficult for parents to have to care for their child 24 hours a day.

The Special Educational Center, ‘Speranta’, was planned in collaboration with the Ministry of Education as a public-private partnership, in response to a request by the parents’ organisation. The government provided a building and undertook to create a fund to finance staffing. A Swedish organisation provided funding for three years and the Ministry agreed to take over the centre’s running costs after this period. One of the aims is to promote de-institutionalisation and the transition to inclusive education.

The centre supports those parents who want their children to be able to attend mainstream schools. The aim is to provide support to disabled children in mainstream schools to make integration easier. One of the problems is that teachers in the ordinary schools reject the children and say, “Well, I’m sorry, but your child doesn’t fit into the class. He is different, isn’t he? He doesn’t meet the school requirements”.

A parent counsellor set up a club for parents and plans to start another club for grandparents who have a very important role in Romania. All these projects are based on the needs expressed by parents and families and on the needs of the disabled children themselves. They have developed in response to members’ changing needs as children have grown older. Parents of older children expressed their concerns: “OK, you are doing all this for children. My child is 20. He was always rejected; there was never anything for young people. So what are you planning for them?”

In response to this need, a centre was established for adults to increase socialisation and integration in the community. It also teaches vocational skills, supports families by providing a respite of eight hours a day, and helps them to understand the needs and potential of their children.

These examples from South Africa and Romania illustrate the urgency that parents often feel to set up services for their children, as this makes their day-to-day struggle for survival a little easier. The next chapter shows that it is possible to achieve a balance between focusing on the basic need for survival and campaigning for inclusion at a local and national level.



Questions for discussion

- Should parents develop services for their children?
- How can parents ensure that governments take responsibility?
- How can parents benefit more from income-generating schemes?
- Is it reasonable to expect parents, and mothers in particular, to work so hard for their children?
- How can parents work with community leaders towards the inclusion of their children in society?
- How can parents of disabled children motivate all parents to promote more inclusive practices?
- How can parents work use resources of other community-based organisations?



Notes

In ‘Empowerment’ parents in Lesotho focus on empowering family members and disabled people themselves to advocate for inclusive services – rather than providing separate services, as in ‘Survival’.

Empowerment

The UN Convention on the Rights of the Child (UNCRC) recognises the role of parents, family and community in supporting the growth and development of all children.

Article 5 talks about “parental guidance and the child’s evolving capacities”: the state must respect the rights and responsibilities of parents and the extended family to provide guidance which is appropriate to the child’s evolving capacities. Article 18 talks about “parental responsibilities”: parents have joint primary responsibility for raising the child, and the state shall support them in this. The state shall provide appropriate assistance to parents in child-raising.

Parent empowerment, Lesotho

Parents of disabled children, and those with difficulties in learning, tend to lack confidence about their rights and responsibilities. Professionals can sometimes disempower families and communities with their apparently superior knowledge. Strong leadership is crucial if advocacy organisations are to bring about changes in the lives of their children. The support of regional and international networks can also play a crucial role (see ‘Networking’ p67). This section describes the process of parent empowerment which has enabled parents in Lesotho to fulfil their responsibilities to their children.

Our main focus is on the empowerment of parents and families and disabled people themselves to cope better with daily living and to advocate for inclusive services.

In the late 1980s a strong disability rights movement emerged in southern Africa, which campaigned for the rights of disabled people. The people of Lesotho were familiar with the language of human rights and social justice because of living so close to South Africa, with its long struggle for liberation. The disabled people likened their own experience of exclusion to that of apartheid, where people were discriminated against on the grounds of ethnicity.

Lesotho is a mountainous kingdom surrounded by South Africa. It suffers from extremes of temperature, is recognised as being one of the world's least developed countries, and has a large migrant workforce. Recently the country has experienced periods of political instability.

A national parent organisation was established in Lesotho in 1992, in close association with the Lesotho National Federation of Organisations of Disabled People. The Lesotho Society for Mentally Handicapped Persons (LSMHP) learned to speak the language of rights and empowerment, and has become an important partner of the Ministry of Education in promoting more inclusive practices in schools and society.

This organisation is an example of the empowerment model, where the parents see their role as lobbyists. They have lobbied for their children's right to access services provided by the government.

The empowerment of parents and families is the main focus of the organisation. Empowered parents are more able to demand services for their children. They are less likely to become caught up in service provision themselves. Instead, they are working in partnership with the Ministry of Education's Inclusive Education Programme. They have realised that they have valuable skills to offer.

The Ministry of Education has been responsible for introducing inclusive practices into 60 primary schools, out of a total of 1,000. It is the ministry's policy to expand this programme to all schools, but they have a limited capacity. Only a small number of education officers are responsible for promoting inclusive education at central level. By contrast, LSMHP members are able to reach schools in areas of the country where they have members and active local branches. In this way LSMHP is helping to promote the expansion of this inclusive policy beyond the 60 schools already involved in the programme.

The Parent Mobilisation Resource Group (see p70) has defined parent empowerment as follows:

"Empowerment is a positive change of attitude and approach that has taken place within a parent who feels that he or she has the knowledge,

power and will to bring up his or her disabled child with the same dignity as other children, even though it might take a lot of patience and hard work."

The Oxford English Dictionary defines the word 'empower' as follows: to authorise, give power to, enable.

Palesa Mphohle, of LSMHP, has identified what it means to be an 'empowered parent':

An empowered parent

- knows the rights of her/his child with disability
- knows about existing facilities and services for his/her child in the community and how to use them to benefit the child
- knows what is good and what is wrong for the child and is confident enough to say "No" to what is wrong
- can guide and gain the goodwill of other parents and the local community in helping and supporting children with disabilities
- explores national laws and policies to find out how they protect and serve her/his own child and other children with disabilities
- knows the channels whereby to seek justice for her/his child
- understands that a child with special needs does not need a special environment, but assistance and support to benefit from the same environment as everyone else
- has the courage to promote the inclusion of a child with disability in his/her family as well as in the community, and to seek to enforce this, even in the local and national government
- understands that a child with disability deserves the same dignity as other children
- understands the concept of human rights and social justice and that disability is not an individual issue, but is a social issue

- can contribute equally to the resolution of her/his child's problems and would not just take instruction from professionals
- understands that getting rid of barriers to the inclusion of disabled children does not depend only on an individual, but on the community.

Palesa Mphohle, 1995

Gathering and providing relevant information has been invaluable in advocating for disabled children's rights.

Parent empowerment is a key factor as it enables parents to act on information and plan collectively how to overcome the obstacles we encounter.

DI CAG,
South Africa

Parents as trainers

The parents in Lesotho have become empowered through meeting regularly to discuss the issues that face them. Since most of the parents have children who have severe learning difficulties, they have had to learn to be advocates for their children. Articles 12 and 13 of the UNCRC refer to the child's right to express his or her opinion and to have freedom of expression. However, in the majority of cases, the parents have been the main channel through which their children have expressed themselves, at least initially.

The parents felt that they needed training in order to be able to speak confidently on behalf of their children to medical and educational professionals. With the support of the Norwegian organisation, NFU (see 'Resource organisations' p.112 for more details), they identified their needs for training and set up the Parents as Trainers initiative.

A group of key parents, known as 'resource parents', were trained to become trainers and to pass on their knowledge and skills to other branch members of LSMHP. The aim of the one-week training course was to help parents gain confidence to enable them to communicate effectively with teachers and other professionals and with other parents, and to pass on their knowledge. The workshop was led by three outside consultants in partnership with local personnel. The emphasis was on learning by doing.

The parents learned how to

- make introductions
- talk about parents' experiences
- ask and answer questions
- present information
- make and use visual aids such as charts and posters
- lead discussions
- use video
- organise and evaluate training.

A group of professionals from the Ministries of Health and Education, and a group of new parent members of LSMHP, were invited to a presentation on the last day as part of the training workshop. The feedback from the professionals was very positive. They now realised the value of what the parents had to say. This experience was captured on video.

The resource parents therefore had a real experience of organising, preparing and delivering a training event. They were also invited to draw up an action plan of activities which they intended to set up in their local areas in the following six months. They were offered ongoing support in carrying out these plans by local tutors and one of the consultants. They practised the suggestions made in the workshops with their own children, and also offered training to 20 other parents.

This training included the following topic areas:

- What is disability? Both the medical and social causes of disability are taught. We explain that it is "normal to have a child with a disability"
- Activities of daily living (ADL) skills: information and advice about feeding, positioning and behaviour management
- Counselling: this deals with the grief, trauma, blame, shame and confusion that often accompanies the birth of a disabled child
- Rights: familiarisation with the relevant laws and documentation
- Approach to professionals
- Enrolment of children with disability in regular schools
- Organisational development: how to mobilise other parents and how to advocate for the rights of children and lobby for services.

We have gained confidence through the education and training we have received. We are now able to advocate for our children's rights.

Parents have now become confident enough to confront teachers who did not want to know about children with disabilities, and who rejected them. Previously the parents would have been very upset about the rejection, but would have just accepted it, and left the school feeling powerless. Now it is different.

It was not only a question of bridging the gap between parents and professionals, but also of understanding the role that parents could play in bridging the gap between the children and their teachers.

LSMHP has embarked on some research to find out more about the situation of families needing help with early intervention. A Community-Based Parent Empowerment Programme has been set up to increase families' access to existing service provision and to place the emphasis on the need for parents to lobby for improved services.

These research and training initiatives have been crucial milestones in LSMHP's development and progress. They have helped to empower, train and build capacity in the organisation.



Questions for discussion



- What do you understand by empowerment?
- What can be done to empower parents in your situation?
- Is it appropriate (in your context) for parents to talk of their children's rights to education and healthcare?
- What are the advantages of parents working in partnership with disabled people's organisations, or other community-based organisations?
- How can parents work in partnership with professionals?

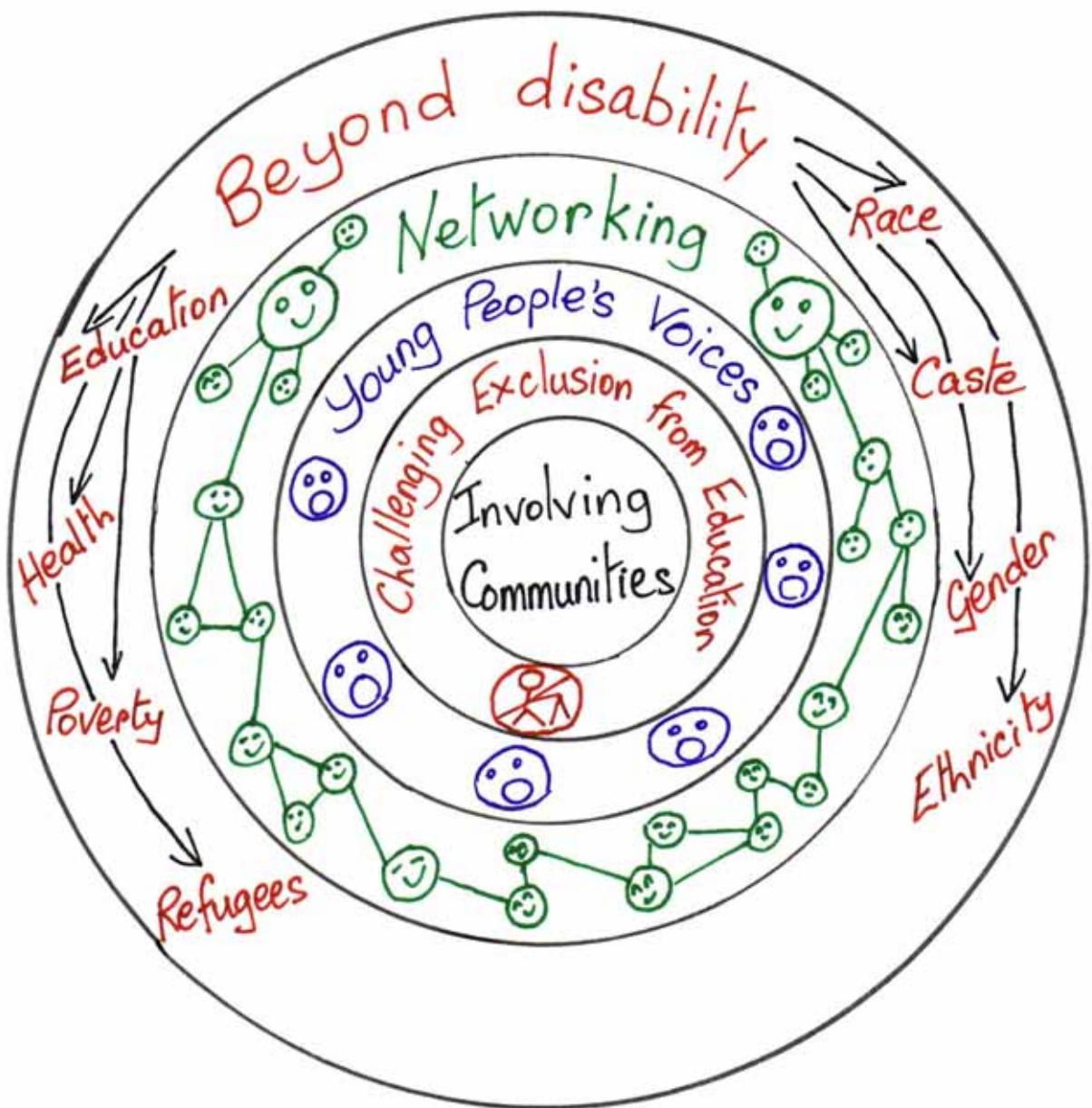


Notes

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Part 2

Reaching Out



In ‘Community involvement’ we hear about a community-based organisation which advocates for the inclusion of disabled children in their local schools. Its membership includes disabled people, parents and other family members.

C ommunity involvement

Advocacy organisations tend to be based in capital cities and have branches in small towns and rural areas. Families of disabled and other marginalised children may also be part of a community-based organisation, such as a community-based rehabilitation (CBR) programme. CBR programmes usually involve parents in the running of activities and often help to form parent groups.

Child-to-Child² methods can be used to encourage children to become involved in promoting inclusion in their schools and communities (see ‘Voices of young people’ p.61).

Children are extremely valuable human resources, yet they are often overlooked and few people ask their opinion. Where there are too few teachers, and class sizes are very big, it is particularly important that children play a greater role.

Family involvement in education – Pokhara, Nepal

Nepal is one of the poorest countries in the world and the disparity between its rich and poor inhabitants is increasing. The population of Nepal is about 23 million. About 90 per cent of the population lives in villages, with agriculture as the main livelihood. The mountainous terrain and poor transport and infrastructure further exacerbate the situation for poor people.

² Child-to-Child was launched in 1978 in preparation for the International Year of the Child in 1979. It is an approach to health education and primary healthcare spread by a worldwide network of health and education workers in over 60 countries, co-ordinated by the Child-to-Child Trust. The Trust is an independent charity, based in the University of London, which designs and distributes health education materials and advises on the implementation of Child-to-Child projects.

The education system in Nepal is under-resourced, hierarchical and examination-focused. A child who fails the end of year exams is held back, and may remain in the same class with much younger students for several years. Primary education is only free in 15 of Nepal's 75 districts which have been designated compulsory education districts. For many children school is neither accessible nor relevant. In rural areas the literacy rate is still only 33 per cent (10 per cent for girls). There is a very high dropout rate, with only 37 per cent of primary school children completing education up to the age of 13. One of the reasons for this is that children are needed to do manual work, especially in the villages. There is also a general belief that it is not necessary to educate girls, members of lower castes³ or disabled children.

Community Based Rehabilitation Service (CBRS), a community-based organisation, has been working for, and with, disabled children and their families since 1995. CBRS clients have physical disabilities and/or learning difficulties, and CBRS networks with, and refers to and from, other local organisations working with other types of impairment. CBRS works closely with the families of disabled children in all activities, such as community awareness, home visits, and parent groups for self-help and advocacy.

An advisory group gives parents and disabled people a direct 'voice' in the running and management of CBRS. The members, both men and women, represent different castes, disabilities and parent groups. This forum meets every two months to consider disability-related topics and project activities, and to plan and make joint decisions.

During the last two years CBRS project staff have worked together with parent groups and local education officials to enable disabled children to attend their local schools. Support to students, teachers and families is offered through a variety of activities, including teacher training and awareness programmes in the schools attended by disabled students.

This informal teacher-training programme has had good results in motivating and supporting teachers. Previously they had no additional support or training to teach disabled students. An important focus of the training has been to develop the role of the teacher as a resource person for the whole community and to work much more closely with the child's family. Gradually, more disabled children are starting to study in mainstream schools with the co-ordinated support of both families and CBRS project staff.

It was in 1997 that discussions were first held with parent groups and a special education adviser from the Ministry of Education. Parents shared their ideas and considered some different models of education.

³ Caste is a hereditary social class. There is little mixing between castes.

Parents identified some of their most common feelings and wishes

- We want our children to receive an education.
- The development of opportunities to go to school should be a joint effort between the government and the local community.
- Our time is limited, but we would like to play a part in the life of the school.
- Our knowledge about our own children is important and should be conveyed to teachers so that the children's education and quality of life can improve.
- We would like to see that teachers are willing to work with us.
- Local recruitment of teachers would help promote stability and co-operation.
- A member of the District Education Committee, ideally a parent of a disabled child, should be appointed to represent the children with special needs.
- We prefer school models and systems where our children remain with us in the family setting.
- We would like to see the children learning things to help them contribute to the family and the community, especially those in rural families.
- We would like to see more skills training in the curriculum, and not just academic content.

In October 1999, teachers, children and family members were invited to voice their opinions during a training course. To include all these groups together was a new idea and could have proved difficult within the very hierarchical structure of the education system. For some families and teachers, this was the first time they had met, despite living in the same communities and being involved with the same children! This is what the children and their families had to say:

Family members

We like our disabled children going to school because...

- the child can learn to read and write, play and have fun
- the children themselves ask to go to school
- their habits (eg washing, dressing) improve
- the children like to be with ordinary children
- their ability to play improves
- their walking improves
- it's good if the child can study to the highest level that school offers
- the siblings of the disabled child also started to attend school.

Children

We like going to school because...

- we can study and play
- I can sit with my friends
- I like to see my friends fight and play
- I like writing and playing ball.

This was very new and exciting for everyone. The risk was worth it:

- to see teachers listen to what the families and children had to say
- to let families in their turn hear the teachers' perspectives
- to see the groups share their experiences and discuss issues openly for the first time.

For more details of these discussions, see 'Parents' Wishes' listed in 'Useful publications' p.101

The invitation to participate in the EENET project, Family Involvement in Education, in 1999, stimulated a lively discussion among members of the advisory group. One of the discussions was about the new compulsory school system which will enable more children to attend ordinary schools in future. But parents also expressed their fears:

Some of these fears included:

- In town the child may be able to get to school in a wheelchair but in the village there are no flat roads.
- It is not easy. We see problems mostly with people's attitudes, including the teachers'.
- You do see bad attitudes and very traditional views.
- When my son falls down, as his muscles are quite weak, often people will not help him up as they are afraid they will catch something bad from him. He doesn't like this and says, "I am shy, mum". This also means that he doesn't really like to go to school.
- It is very hard for the child if they get teased and we know that the teacher will sometimes take part or even start the teasing!

But parents also feel that attitudes are slowly improving:

Now that there are some projects like CBRS – slowly people are learning more and becoming more understanding.

They appreciate the efforts and flexibility that enable some children who cannot get to school to learn at home:

It is quite amazing what can be done with lots of practice and effort. In our district, there is a girl who has no hands and she does everything with her feet – eating, brushing her hair, everything. She has just passed her

school-leaving exams. A lot of time and energy had to be put in to achieve this. We should try to do the same for our children and work with CBRS field staff to get the best benefits.

The practical financial problems of many families have also been discussed. As a result, the project started a new scheme to help the poorer families find money for school fees, school uniform and stationery, either from local government or other sources. In Nepal a child may be sent home from school if he or she does not have a uniform, yet some families cannot afford the clothes. (For more discussion about this issue, see 'Beyond disability' p.75)



Questions for discussion



- How can the children in your community play a greater role in their own education and in the promotion of education for all?
- Which other community members could provide support to the inclusion of marginalised children?
- How can community members become more involved in training teachers and raising their awareness?
- How can existing community development and advocacy programmes become involved?



Notes

In 'Challenging exclusion from education' we hear from South Africa, Lesotho and Australia where parents have campaigned tirelessly for their children's inclusion in education.

C hallenging exclusion from education

Article 2 of the UNCRC is one of the most important for marginalised children as it deals with non-discrimination. It states that all rights apply to all children without exception. It also states that it is the state's obligation to protect children from any form of discrimination and to take positive action to promote their rights.

Articles 28 and 29 deal with education and its aims: the child has a right to education, and the state's duty is to ensure that primary education is free and compulsory. The state shall engage in international co-operation to implement this right (Article 28). Education shall aim at developing the child's personality, talents and mental and physical abilities to the fullest extent (Article 29).

Education is usually a key issue for advocacy groups. It is a fundamental human right that every child has access to education. In countries where many children do not attend school at all, parents often find themselves challenging the system to accept disabled children, those with difficulties in learning, and other marginalised groups. Some advocacy groups have preferred to set up their own schools, believing that this is the only way to guarantee that their children get an education today. Campaigning for change tomorrow may not benefit their children.

Where education is compulsory, parents still campaign on educational issues. The organisation Parents for Inclusion in London, UK, for example, supports parents who want their children to attend their local school rather than a special school. Parents are also given support when their children are being excluded within a so-called inclusive situation.

Although some advocacy organisations have been specifically set up to address educational issues, most groups are concerned about a range of issues, not just education. Education is only one part of a child's life, and should be seen in the context of other needs, such as the need for love, security and a family life.

In South Africa, Lesotho and Queensland, Australia, parents have lobbied government education departments to become more inclusive. All three advocacy groups prioritise educational issues. They have been successful in influencing and supporting change in the education systems and schools where they work. But it has not been easy.

Enabling learners, South Africa

In 1996 a new Education Act was passed to begin to redress injustices resulting from apartheid. Previously there had been two forms of discrimination faced by disabled children:

- racial segregation through apartheid
- segregation based on the medical model of disability – disability as a medical condition requiring treatment.

School attendance is compulsory between the ages of 7 and 15. All public or state schools are required to admit *all* learners and to meet their educational needs. The Education Act and the South African constitution safeguard the right of *all* children to education. However, many groups of children are still poorly served by the current education system. Estimates suggest that only ten per cent of children under six have access to early childhood development programmes, and, in one particular province, less than one per cent of disabled children, according to a recent survey.

Parents in the Disabled Children's Action Group (DICAG) have high expectations:

We expect our children to have access to appropriate education and all teachers to be adequately trained to meet the diverse needs of all the children in their classrooms. We expect transport to be made available, as the difficulty of getting to and from school remains a major barrier to education.

Education has been a priority from the outset. The aim is to ensure that all children have access to a range of educational opportunities that can best help them fulfil their learning potential. In order to achieve this, DICAG tries to ensure that all children with disabilities are given the opportunity of an

early start to education through early childhood development programmes and facilities that can offer early intervention and stimulation.

DICAG's concept of education is broad. The parents emphasise the importance of stimulation for children with the most severe physical and learning disabilities: to enable them to respond and communicate their needs; to communicate in a wide variety of ways; to be as independent as possible; and to develop their potential. These are all vital educational goals.

DICAG's story of helping to establish a barrier-free primary school in Kamagugu

DICAG has helped us to include our children. We already see lots of change in our children. We are so proud!

We experienced serious problems in trying to enrol our disabled children in public schools in Kamagugu, a suburb of Nelspruit, the capital of Mpumalanga Province. Even when we succeeded in finding a school to accept our children, there was the problem of getting there as none of the schools was within walking distance of Kamagugu and we had no transport. So when the Kamagugu Residents' Committee was set up, education was high on our agenda.

The whole community, and those of us who are parents in particular, have been very much involved in promoting a culture of learning, teaching and service within Kamagugu. Estimates suggested that as many as 80–85 per cent of disabled school-age children were excluded from school and formal education. Deaf and blind learners faced virtually total exclusion. The province had no facilities, such as Braille or independence training, for learners with visual disabilities, and no sign language for deaf learners.

Four major disabled people's and parent organisations came together to form the Mpumalanga Special Education Initiative Voluntary Association to develop strategies to gain access to education for disabled learners, as well as to try to set up pilot projects to demonstrate good inclusive practice. A grant from the Independent Development Trust for the building of classrooms provided funds to support this initiative. We decided to use the funds to educate deaf and visually impaired learners within inclusive learning environments.

Many parents of non-disabled children were against the idea of inclusion.

They feared that disabled children would “spoil” their children. Now all parents are very willing to take all their children to that school.

We set up a steering committee, consisting of representatives of residents, parents and special education professionals, to take responsibility for the development of a new local school. The committee has adopted the principles of non-discrimination, inclusion, community involvement, excellence through partnerships, and participation and social integration.

We planned barrier-free school buildings and tried to get additional funds and donations. We organised meetings with the local community to explain our aims and ideas for the school and all this activity mobilised support. The soil-turning ceremony at the start of building the school received considerable media coverage in the province. Further donations have enabled us to buy essential equipment.

Kamagugu Primary School is the first multilingual school in the country, with South African sign language⁴ as a medium for teaching and learning. The school tries to be inclusive, with both disabled and non-disabled pupils. This initiative has already led to further plans for the establishment of other schools in the province, which will be resourced to include disabled learners.

DICAG supports local groups by informing parents of their children’s rights to education and by providing training as well as advice on how to mobilise other parents of disabled children to be active in relation to issues that affect their children’s development.

Partnership with the Ministry of Education, Lesotho

Education has been a priority from the very beginning. A key article in our constitution states that society exists to support our children’s inclusion in schools, in employment and in the community as a whole.

⁴ Sign language is used by deaf people, instead of, or in addition to, spoken language. Each country has its own sign language.

The Ministry of Education started an inclusive education pilot project in 1991 in ten schools – one school in each of the ten districts in Lesotho. All the teachers and headteachers in each of the ten schools were trained to promote the inclusion of disabled pupils and those with difficulties in learning in their classes (see *Preparing Teachers for Inclusion*, a video training package listed in ‘Useful publications’ p.101).

In 1993 a Ministry of Education survey found that 17 per cent of children attending primary schools had an impairment, or some difficulty in learning. It was not necessary to go out looking for children who had difficulties in learning – they were already in the schools – but no one had noticed that they were experiencing difficulties.

In Lesotho only 25 per cent of children enrol in secondary school, yet nearly 75 per cent of children enrol in primary school. Dropout rates are very high in many countries, but Lesotho is unusual as more boys drop out of school than girls, since the boys are needed to work as goat and cattle herders in remote mountain areas.

We decided not to wait for the results of the Ministry of Education’s pilot programme on inclusive education, but to take action ourselves to promote the development of more inclusive practices.

In preparation for inclusion, LSMHP established an early intervention programme where children are brought by their parents for training in activities of daily living (ADL). This programme is run in Maseru, the capital. In some local branches, parents have formed playgroups where they get together to encourage their children to play together and to prepare them for mainstream education. Recently the emphasis has changed from holding regular meetings to enabling parents to stimulate their own children and address their developmental needs.

Members of LSMHP support each other by visiting local preschool facilities, primary schools and vocational institutions to seek placement for children with disabilities. After admission, regular follow-up visits are made to monitor their children’s progress.

The most heartening experience for parents is when teachers include their children in the classroom and encourage other children to work with them as classmates.

At first, teachers were reluctant to accept children with learning difficulties, but now they even teach their pupils how to help children with disabilities. Gradually things are improving. Government policy on more inclusive education is being put into practice.

Our children are now accepted in schools and there is increasing support in the community. Before, our children were made to repeat the same class over and over. Now they are able to move within the school and can earn promotion from one class to another like any other child!

The inclusive education project has been helpful in reducing the high dropout rate, by raising educational standards. Teachers feel that they are better qualified to teach all children now that they are more aware of the individual differences between children.

When a teacher claims that he or she isn't trained to work with disabled children, we say that we also weren't trained to raise a disabled child!

Not all children are able to attend school. The most severely disabled children are still excluded from any kind of education in Lesotho and remain at home. Other disadvantaged groups are herd-boys and children with HIV/AIDS. Many children do not attend school because their parents cannot afford the school fees. However, school fees were abolished in 2001 for all children starting school in that year. By 2006 all primary school education will be free.

My child is not in any school. The teachers told me that they felt unable to help because the disabilities my child has are too complex and severe and they have insufficient training to understand and cope with them.

Inclusion means being together. They learn something from us and we learn something from them.

The word for 'inclusion' in Sesotho, the language of Lesotho, is very long. Its meaning is broad and includes non-discrimination and being accepted by everyone with whom we interact. It includes mutual learning with, and from others, and equal rights.

From a discussion with
young people, 1999

A mother's story

A mother visited the local school. The teachers were friendly and welcomed her until she mentioned that her child was disabled. They said, "*Do you think we will teach a child with disabilities? If the headteacher hears you he will chase you away!*".

So she went away from the school and returned to her home. What could she do? She sought out a teacher in the community and asked her to talk with the school about integration and the teacher agreed. The teacher was also rejected and sent away.

She tried a third strategy. This time she went to the local chief and told him that of the three schools in the area, one school was refusing to accept children with disabilities. The chief went to see the headteacher and threatened to report him to the Minister of Education! The headteacher was not dismayed. He did not care. He said, "*I don't want my school to teach stupid children!*".

A few months later the chief contacted the mother and advised her to return to the school. A new headteacher had been appointed! She went to the school and when she arrived she was overjoyed to find that four children with disabilities were already included as pupils of the school!

Inclusive education for all, Queensland, Australia

In 1986, Queensland Parents of People with a Disability (QPPD) began to lobby the Education Department to take responsibility for the education of students with learning difficulties. In the same year an education subcommittee was set up within QPPD. This is the story of many years of lobbying.

We had representatives on about 19 state education committees, including advisory committees. The aim of these representatives was to obtain information and learn how to lobby and advocate. Prior to this, students with learning difficulties were ignored by the system. Privately-run, segregated 'sub-normal centres' were the only form of stimulation that a few children were receiving. The focus of 'inclusion' at this time was to pressurise the government to take responsibility for *all* students. Special schools existed, but had primarily supported students with physical disabilities.

A milestone came in the early 1990s when we became very concerned that a considerable number of disabled children were being excluded from their local schools. A meeting was called for all the parents who told their stories and described their dreams for their children. It was an informal group of interested people who wanted change in the education of children with disabilities. We drew strength from each other and got to the point of trying to clarify our vision and our values. We developed a collective voice to try to influence government and the policies of the day. The Inclusive Education Network was born!

All children with all disabilities should attend their local school. The only criterion was that they could breathe – whether assisted or unassisted. In other words, just the fact that they were alive!

Our parents want the same for all their children, whether disabled or not:

- to be accepted at the school as an individual with their own uniqueness
- to be welcomed and given the same opportunities as others
- to be valued for who they are and not cast aside because of their label.

The group now has 80 members and 10 members from all around the state of Queensland come together by telephone on a monthly basis to share their experience, the challenges, and what is happening in their locality.

We organised a city centre rally with press releases, literature, and a banner made up of all the faxes sent in support of students' desire to go to an ordinary school. It was huge. There were hundreds of faxes. We drew on the Salamanca Statement. The rally culminated in a march to the Education Department building and its leaders tried to present the statement to the Minister.

Our main struggle is against hostility to inclusion.

In 1994 some members of the group were invited to speak to parents at a special school who were very pro-segregation. We encountered considerable hostility and verbal abuse, but it was an important learning experience. In the same year, QPPD launched a document called *Inclusive Lives* and a public campaign about inclusive education. This led to a strong backlash from the Queensland Teachers' Union who started their own active campaign against the inclusion of students with disabilities in mainstream schools. The anger that the group experienced surprised us at the time. We were just some people who wanted better lives for our sons and daughters. We've learned from that experience about the ebb and flow that movements experience.

Another crucial challenge became a test case in Australian education law. One family, who were experienced members of QPPD, challenged their local school's right to exclude their daughter, after a long struggle during which they tried to work in collaboration with the school:

We plodded on and kept trying to work with the school and the teachers, encouraging them, informing and educating them along the way because they were quick to point out that they had no knowledge of anyone like my daughter. Initially our daughter was only allowed to attend regular school on a part-time basis, with two days in a special unit.

In her second year she was allowed to attend the regular class full-time but after six months they excluded her for behaviour that was prejudicial to the good order and conduct of the school. They objected to her singing in class and having to be taken to the toilet on an hourly basis. In spite of the fact that our daughter did not have a severe disability and we had been told that we had a good case, we lost our court case. We were very upset!

QPPD has developed the following strategies to address these challenges:

- keeping abreast of policies
- widening the membership
- organising public awareness activities, such as public rallies
- producing publications with a positive message
- sustaining the commitment
- paying a worker to support the group's activities
- holding information mornings to encourage parents to understand what inclusion involves for their particular child, and to join in the broader work of systems advocacy.

An important part of the overall strategy is that members always attend meetings as a small group; prepare themselves for meetings with professionals and statutory bodies; and have debriefing meetings afterwards to further develop their lobbying strategies. In this way they ensure that their message is consistent.

Members are very passionate about the cause and what they believe in, and about their dreams for their children.



Questions for discussion



- What role do you think parents can play in promoting inclusion in education in your country?
- How can parents be supported to work in partnership with teachers?
- How could you tackle hostility to inclusion in your context?
- What could you do to make sure that severely disabled children, or children from other very marginalised groups, get the same opportunities for inclusion?



Notes

In 'Voices of young people' we hear from school children involved in a Child-to-Child programme which promotes inclusive education in a school in Northern Zambia. We also hear the personal story of a severely disabled young woman from Lesotho who attended her local school with the support of her peers.

V oices of young people

We have begun to actively seek the views of disabled learners themselves. At a recent workshop many children with cerebral palsy and other disabilities expressed their dreams and ambitions. Most children wanted to enter higher education and expected education to give them the opportunity to obtain employment. Deaf children expressed dissatisfaction with the low level of signing among their teachers!

DICAG,
South Africa

We are committed to self-advocacy, but recognise that parents are required to speak on behalf of their children.

LSMHP,
Lesotho

While it is important that parents speak on behalf of their children, and empower them, it is also essential that children and young people speak for themselves. Parents are often accused of being overprotective of their children, and of not having sufficient understanding of disability and marginalisation. However, parents are increasingly becoming more aware of their children's rights and are playing an empowering, rather than an overpowering, role.

In this chapter we feature the 'voices' of Zambian children who have participated in the inclusion of a child with learning difficulties using Child-to-Child principles; and the story of a physically disabled girl in Lesotho

who had a very positive experience at her local primary school, but who experienced hardship at secondary school, where she was a boarder.

Child-to-Child in action

Paul Mumba's story, Mpika, Zambia

Central to the Child-to-Child philosophy is a belief in the power of children to communicate health messages and practices to younger children, peers, families and communities. The undemocratic practices in most classrooms, however, has proved to be a major barrier to the effectiveness of Child-to-Child methods. Most teachers prefer the traditional way of teaching. After all, why should teachers contemplate putting themselves on an equal footing with a child when African societies emphasise authoritarian interaction between adults and children?

I am a teacher in Kabale Basic School, Mpika. In my role as Child-to-Child co-ordinator, I have tried to address the following questions:

- How can children's rights be promoted in primary classrooms?
- How can girls participate, so that boys fully appreciate girls' contribution in learning?
- How can parents and children be helped to participate in the syllabus of the local school?
- How can children with learning difficulties be supported within the class?

Rights: I began by creating awareness in children of their rights, as documented in the United Nations Convention on the Rights of the Child. This was done through class discussions in their spiritual and moral education studies lessons. The children discovered that each right had responsibilities that went along with it and they became more responsible and critical. For example, the right to education carries with it the responsibility to work hard at school, to avoid absenteeism and to go to school on time. The children's attendance improved enormously as a result of these discussions.

Working in groups: In my class I introduced group evaluation in the form of a graph. Each child is given an individual mark and then an average is calculated for the group's performance. The groups are then compared. This caused concern for faster learners, as they did not want their groups to be associated with failure. They became motivated to help the slower learners in their own time and in their own homes in order to improve the performance of their groups.

Inclusion: After including the children labelled as having learning difficulties in my class full-time, they refused to go back to the unit which had been created specially for them. I designed curriculum materials which helped to introduce the concept of inclusion. For example, the children carried out a survey of children with learning difficulties who were excluded from school. This became a maths lesson, and a study in geography and in social studies. I developed English comprehension exercises about the inclusion of children with particular learning difficulties. Here are some of the responses written by children in my class to the question: "*How can you help to include Bwalya in our learning so that all children benefit?*"

Play: Football; running; drawing; singing songs; playing chess; reading; riding a bicycle; handwriting; counting numbers; covering the books; showing him how to make toys from soil.

Home visits: Visit him at home on Saturdays.

Making him busy: So that he likes school; we want him to be happy; we want him to know more things.

Being friendly: By showing him good behaviour; by giving him gifts; by showing him happiness; by coming closer to him; by helping him with things he doesn't know; by reading him some stories.

Mamello's story, Tanka, Lesotho

Mamello was supported by the Scott Hospital CBR team to attend her local school. Mamello had a severe form of brittle bone disease. She was educated at home by her friends long before she was provided with a wheelchair and given a place in school. Mamello's story illustrates the ability and willingness of children to help each other. It also highlights the difficulties for all children of attending schools where there is little

awareness of difference, the atmosphere is unwelcoming, and children are beaten.

I was taught how to read and write by my best friend - we used to play together all the time. We played with dolls and I taught my friends how to sew clothes and knit jerseys. We started a choir and were joined by many children. Teachers from Tanka Primary School visited us and gave me some work to do. They told me to attend school in 1994, at the age of 15. I started in Standard 5.

At primary school I was cared for by teachers and other children. At that time I liked school very much. I was able to help my teacher in teaching others and it helped me to know more things and remember them all the time. I was able to pass Standards 5 and 6 in position 1, and first class in Standard 7 (the last year of primary school).

When I completed primary school in 1997, I went to a boarding school at Motsekua. At first I did not apply to this school because I heard that there was bad treatment of Form A (first year) students. When I heard that I had a place at Motsekua, I felt that it was better not to attend school, but my friend told me that she would take care of me. LSMHP paid my school fees for the first three years. I was not treated badly, but we had to wake up very early every day. Some teachers didn't beat me when I failed to answer their questions or failed their subjects, but others did beat me. When they entered the class I was not thinking about their subjects, instead I would be thinking about how they would beat me when I failed to answer their questions.

Some children became my friends, while others would be calling me names. I told the teachers, and they beat these children and told them not to do it again. Sometimes other children, who were not my friends, took me to the toilet and helped me onto my wheelchair. In 1998 I had a problem with my friend who was taking care of me. She became pregnant and left school. But I had another friend, who was also disabled, and she did the same things that my first helper did. I also had a problem with her. She could not finish her schooling because she did not have enough money to pay the boarding fees. I passed Form C (the third year of secondary school) in second class, but I was out of school this year because my mother could not pay the school fees for me and my brothers and sisters. My intention is to finish high school and do social work and help other children with disabilities.

Mamello died in August 2000 aged 21, just a few months after she wrote this story.

We can learn a great deal from her story about the importance of listening to children's perspectives of inclusion and exclusion; about children's relationships with each other; and about making schools more welcoming places for the benefit of all children.

"Some teachers didn't beat me... but others did"

If we are not shocked by Mamello's statement, we should be! It highlights the way children are abused by adults globally, and that this is taken for granted. Being disabled makes children more vulnerable to physical and sexual abuse. This is why advocacy organisations, run by disabled people and parents of disabled children, need to link with child rights groups to campaign against violence and abuse (see 'Beyond disability' p.75).



Questions for discussion



- How can parents encourage their children to express their opinions?
- How can children play a greater role in their own education?
- How can teachers be encouraged to involve all children in their own learning?
- Would it be appropriate in your context to encourage children to take responsibility for the welfare of other children?
- How can children be supported to speak out against corporal punishment in schools, and other forms of violence against children?
- How can advocacy organisations be encouraged to open their membership to young people?



Notes

In this chapter we hear from Romania about the benefits gained from making contact with international organisations in terms of fundraising, ideas, information, and influencing change. We also hear about the Parents' Mobilisation Resource Group, which was a network of parents in Southern countries supported by a Norwegian organisation.

Networking

Following the fall of communism in Romania, parent groups began to reach out to other countries for support. They developed supportive networks. These networks have helped them to bring about major changes in the lives of their children, who were marginalised by society because of their impairments. The following quotes from members of Speranta, in Timisoara, Romania, demonstrate the value of making contact with others.

To learn about new concepts

When we started I had no idea about inclusive education or mainstreaming. I knew nothing about other groups of parents – nothing about the whole philosophy of inclusion. The word 'Inclusion' did not exist for us; very few people spoke about mainstreaming – it was a completely new concept for us.

To identify sources of funds

This strategy of finding resources from outside has been crucially important to us from the start.

To influence change

We developed a deliberate strategy of using our foreign partners to put pressure on the government

here. Romania wanted to join the European Union and wanted to meet the European standard, so we told them that if they wanted to meet the standard they also had to do something for citizens with learning disabilities.

To access information and knowledge

We needed support of all kinds, not only funding and materials, but also access to wider information and knowledge than was available here in Romania.

The Enabling Education Network (EENET) was established precisely because of the need to share information about marginalisation in education. By sharing stories of success and failure in promoting inclusion, practitioners feel more confident about their own practice. They are also able to show government representatives examples of inclusive practices in other countries. Family members often feel very isolated. Hearing about advocacy groups in a variety of countries in the world can help to lessen feelings of isolation.

EENET gives us an opportunity to know how other countries are finding solutions. This helps NGOs and governments to build on their existing strengths. It also stops us from reinventing the wheel, because with information we can achieve a lot by just changing our tyres!!

Indumathi Rao,
Regional Co-ordinator,
CBR Network (South Asia)⁵

To be part of a network is to feel less alone, and therefore to feel supported and encouraged. Networking is a way of reaching out to others, to save re-inventing the wheel.

⁵ See EENET's newsletter 'Enabling Education', Issue 5 March 2001, p 14

We are presently affiliated to local organisations working in both the disability and children sectors, both nationally and at local branch level. We are networking with other parent organisations, regionally and internationally.

LSMHP,
Lesotho

However, networking requires a lot of effort. Since it began in 1992, LSMHP has relied on networking opportunities for advice, direction and information. Often these networks have provided skills training in areas that have been important for the organisation. However, the parents have realised that networking requires a lot of planning and preparation. It is not enough to attend meetings and conferences. Effort has to be made to make the most of these occasions, if the opportunities are not to be wasted. Not everyone has networking skills, but these skills can be developed with practice.

In the box below, you will find a sample networking exercise, which is designed to help you get the most out of your time at a seminar or meeting. It is important to remember that everyone carries with them years of experience and knowledge. Others can only learn from your experience if you share it. In the same way, if there is something specific you want to learn at a meeting, you need to find out which participants have the valuable knowledge that you need. If structured networking is not possible it is still a good idea to prepare mentally for the informal networking which takes place at meetings and conferences.

Networking challenge

You have three yellow cards and three pink ones. You may have more, of course, if you need them! Please write down what you can share with others on the yellow cards, eg experience of community-based work in West Africa. On the pink cards please write what you would like to learn, or find out, from others, eg talk to someone with knowledge of Vietnam. Then stick your cards on the wall under the relevant headings:

I can offer....
I can share....
(yellow cards)

I need....
I would like....
(pink cards)

Remember to write your name clearly at the bottom of each card, so that other participants who read them can ask you about your unique experience, or perhaps give you the information you are seeking.

Some advocacy organisations may not always provide the support and networking that some family members need. There could be a conflict of values and goals between members of the organisation. The following communication from an EENET reader in Latin America illustrates that she has felt the need to network and gain support and information elsewhere, as the national parent organisation does not believe in inclusion or rights, only in service provision.

In our country there is no awareness about inclusion and human rights in the movements of people with disability and their parents. I have just finished my period on the board of the parent organisation and have decided not to participate any more. They fight for money for institutions, but they have rejected the rights issues. I am still in good relations with them, but I will not continue to work with their name. Instead I am now working closely with a child rights organisation, which has, until now, neglected the needs of disabled children. Please keep sending us information about events and projects, and the newsletter; it will be a great support. You can't imagine how isolation feels!

Parent Mobilisation Resource Group

The Parent Mobilisation Resource Group (PMRG) is an interesting example of parent networking. The World Congress of the International League of Societies for Persons with Mental Handicap, renamed Inclusion International in 1995, was held in New Delhi, India, in November 1994. At this congress the Norwegian Association for Persons with Developmental Disabilities, NFU, took on the task of co-ordinating the Parent Mobilisation Resource Group.

A preliminary meeting of this group was held in Spanish Town, Jamaica, in August 1994. The first official PMRG seminar was held in Lesotho in April 1995. Two further seminars were held in 1996: in March in Mauritius; and in September in Zambia, when there was also a representative from Mali. The PMRG had a strong focus on the right of people with learning difficulties to full inclusion, and on an awareness of international documentation. The findings of the PMRG were presented to Inclusion

International's World Congress in The Hague, 1998, and then the group ceased to exist. However, in November 2001 a meeting was held in Johannesburg to discuss the setting-up of a southern African network of advocacy organisations.

The following extracts are from the seminar reports. They express the value and power of networking.

PMRG: Who are we?

- We are parents from parent associations in Jamaica, Lesotho, Mauritius, Norway, South Africa, Tanzania, Zambia and Uganda – two parents from each association.
- We empower parents to advocate for the rights of persons with intellectual disabilities.
- We empower associations in the field of organisational management.
- We develop materials and strategies for parent mobilisation based on our accumulated experiences.
- We aim to establish a core group of parent consultants for the benefit of other parent associations.
- We try to operate through bi-annual seminars and through smaller defined task committees.
- Our results will be available for other countries, regions and languages.
- We offer advice to CBR programmes, in an effort to ensure that parents are mobilised under such programmes.

PMRG Seminar, Mauritius, 1996

Key words in the mobilisation of parents

- information
- education
- detection of barriers
- empowerment
- dedication
- devotion
- action
- mobilisation
- respect
- transparency
- commitment
- involvement
- togetherness
- good leadership
- influence
- advocacy
- effective co-ordination

PMRG Seminar, Lesotho, 1995

In one of the seminars, a vibrant organisation was compared to the water post where people go to fetch water. The organisation is a source of knowledge and information with an atmosphere of sharing and free counselling. It is a point of referral for the mothers, fathers, caretakers and families in search of answers, guidance, comfort and support in their daily lives.

Parent empowerment and mobilisation involves the building of self-confidence by sharing knowledge and information. The aim is to build awareness and influence the capacity of the organisation on matters of social and political justice in the community. Advocacy organisations should be judged according to their capacity to share information and empower their members.

LSMHP's involvement in the PMRG helped to extend its networking from within Lesotho to other countries in Africa and internationally. This diagram illustrates the type of networking that LSMHP is involved in.



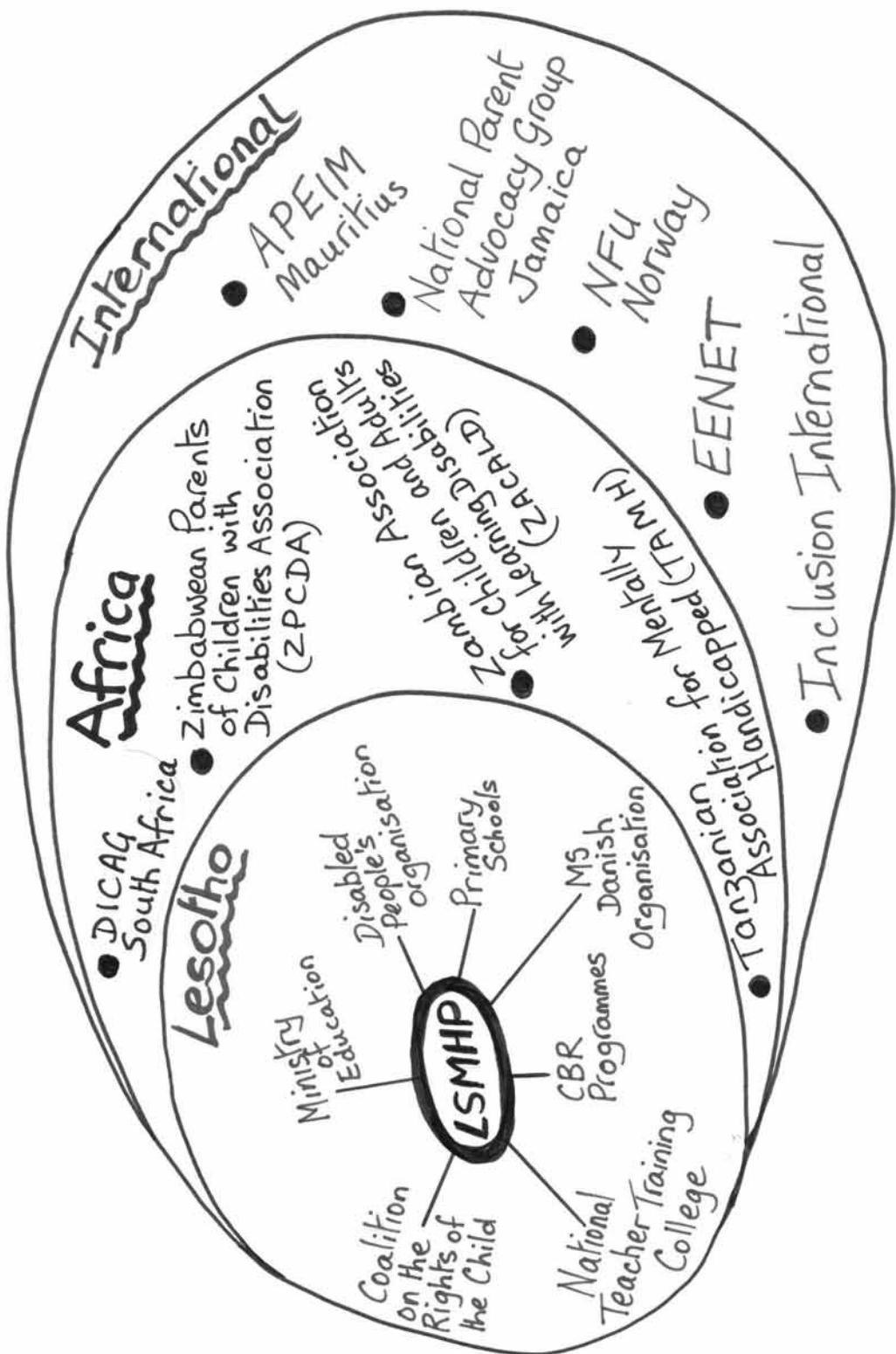
Questions for discussion



- Who do you work closely with?
- Who should you be working more closely with?
- Do you make the best use of the meetings you attend?
- How could you improve your networking skills?
- What national/regional/international networks does your organisation belong to?
- How could you expand these networks?
- Try drawing a diagram which shows the connections your organisation has with other organisations, both nationally and internationally. (See diagram on p.74)



Notes



An example of a networking diagram

This chapter looks at the way in which parents in Lesotho have made links with other organisations working on a broad range of issues of marginalisation; it also highlights key issues of marginalisation in South Africa and presents some possible strategies for raising awareness of these issues.

Beyond disability

On reflection it would have been better if we had trained the teachers to respond to all children in difficult circumstances, and not only those with impairments and difficulties in learning.

Special Education Adviser
to the Ministry of Education,
Lesotho, 1991–95

When EENET embarked upon its Family Involvement in Inclusive Education Project in early 1999, the intention was to collect a range of stories addressing different aspects of marginalisation, not only disability and difficulties in learning. We were unsuccessful, however, in identifying family and parent initiatives which focused on other issues, although gender, ethnicity and poverty issues are addressed in many of the parents' stories. In Nepal, for example, discrimination by caste is a big issue which makes life even more difficult for disabled children and their families. In South Africa, the legacy of apartheid means that ethnicity is still a major cause of discrimination.

In this short chapter our aim is simply to highlight these other issues, and draw attention to some of the advantages for advocacy groups of collaborating with other campaigning groups. This is especially true in countries which have limited access to information and material resources, and where large numbers of children do not attend school.

Awareness of marginalised groups in South Africa

DICAG and other disability-focused groups have ensured that there is some acceptance of the idea that disabled children should be included in a transformed education system. However, this acceptance is not extended to the wide variety of other children who experience barriers to learning.

"Street children are currently not catered for at all, and a conservative estimate suggests there are at least 10,000! Many children who grow up on farms do not attend school. Children in poor rural communities are at risk of receiving no education whatsoever because of the poverty faced by their families."

Parents play a leading role in raising awareness of marginalisation in Lesotho

LSMHP has been at the centre of a national Coalition on the Rights of the Child, established in 1998 as part of the 50th Anniversary of the UN Convention on Human Rights. Its primary aim is to monitor and promote the implementation of the UN Convention on the Rights of the Child.

LSMHP is the only advocacy organisation, predominantly made up of parents, which is a member of the coalition. The other member organisations promote awareness of marginalised children, and of disabled adults, but they do not represent the various experiences of different family members. LSMHP is therefore unique in its advocacy role.

The Coalition raised its concerns about the following groups of children with the Ministry of Education:

- abandoned and orphaned children
- children on the streets
- abused and neglected children
- young mothers, or unwedded mothers
- children with HIV/AIDS.

There was no mention of these groups of children in the National Programme of Action for Children, the Education for All (EFA) country report, and the inclusive education policy, but the needs of disabled children had been raised in the EFA report.

LSMHP has compiled a resource list of surveys, statistics, situation analyses and policies about children in Lesotho. This has been a major contribution to the Coalition. At the same time, disability issues have been raised among the other 30 local NGOs who all have an interest in children's rights.

Through our involvement as parents in the education of our disabled children, we have become more interested in the education of our other children, who are not disabled.

Palesa Mphohle,
LSMHP

Action Learning for Inclusion

EENET has recently set up an action-learning project called, 'Understanding Community Initiatives to Improve Access to Education', or 'Writing Workshops' for short. It is a small-scale project linked to the overall aims of EENET and is funded by the UK's Department for International Development (DFID). Its aim is to help people who are involved in different types of inclusive education to:

- learn from their experience of inclusive practice
- document it
- share it with other people.

The following table was created to help teachers, children and community workers think about inclusion and exclusion as widely as possible. It can help to identify those who are excluded from school altogether, and those who are attending school but who are excluded within the school activities.⁶

⁶ Contact EENET if you would like further information about this project.

Sample table for gathering baseline data

In this district:

Presence	Children who are not enrolled	Children not attending
How many?		
Who?		
Why?		

Participation	Children not involved	Children who feel unwelcome
How many?		
Who?		
Why?		

After filling in this table it is important to check whether you have got the right information:

- What further information do we need?
- Are we sure about the information?
- Could there be other views?
- Are there gaps in our knowledge?



Questions for discussion



- Which children are marginalised, or excluded, in your community?
- Why are they marginalised?
- What can your organisation do to raise awareness of their needs?
- What are the advantages and disadvantages of thinking about discrimination as broadly as possible?

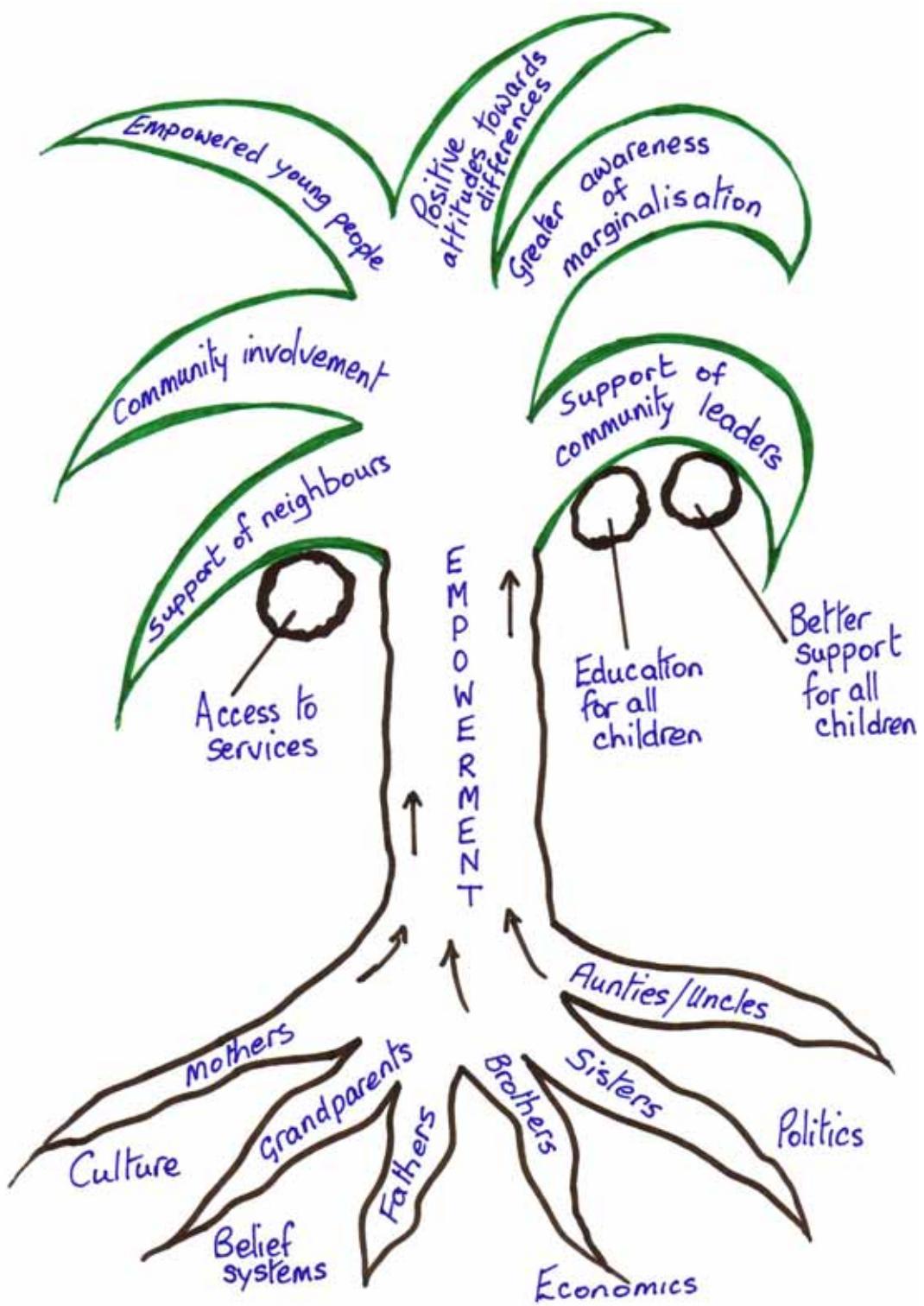


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Part 3

Looking to the Future



Here we share with you the future plans of the contributing organisations, and LSMHP's strategic plan for 2000–2004, as an example of the planned activities of an advocacy organisation.

Vision for the future

CBRS, Pokhara, Nepal

- continue to help children to be placed in ordinary schools and raise awareness of disability among other students
- identify more educational opportunities outside the formal school context
- provide financial help to poor children, especially in the villages
- enable children and young people to study locally
- help to obtain equipment
- promote good role models of disabled people who have studied and achieved, such as Mr D, who is a university teacher in Kathmandu and has artificial legs. This can motivate others, including families who may think that their disabled family member cannot do anything
- find sponsors for individual children and ask schools to give scholarships
- lobby government to give personal allowances for disabled students; to offer incentives to schools to accept them; and to improve education services for ALL children
- continue the programme of training teachers with the participation of families and disabled children themselves
- develop a curriculum and learning materials to enable other projects to run training programmes.

QPPD, Queensland, Australia

There are a number of tasks ahead:

Promoting inclusion and resisting segregation

Although there are now more policies and legislation supporting education for children with disabilities, there is a trend towards segregation. This is because of the way resources are being directed. Resources are mainly provided in separate settings, or in small settings on mainstream school campuses. The rationale is that resources need to be clustered, but that means that students must receive their education at designated sites. One of the main tasks of QPPD will be to 'stem this tide'.

Seeking support from wider groups

We will seek support from professionals – both academics and educators.

Liaising with similar groups internationally

If it is known that there is inclusive schooling in 'less developed' countries, then our country has no excuse!

Lifelong learning

We need to look beyond primary and secondary education and beyond schools altogether. Young people have needs for leisure, recreation, sport, community access, employment and further education.

Challenging the barriers in further education

Most technical and further education courses for people with disabilities are inappropriate and of poor quality. We have much work to do here.

Speranta, Timisoara, Romania

- continue to lobby the government to keep learning disability on the agenda
- seek increasing resources to maintain the services which already exist and find solutions for those needs that remain unmet
- recruit additional volunteers to sustain and increase the work of supporting families, both materially and emotionally.

TREBUIE!, Bucharest, Romania

"The struggle continues and the future is uncertain. When my daughter is 11 years old she will be required to achieve a certain level of attainment in many new subjects, and it is unlikely that she will be allowed to stay in the mainstream. I will be forced to agree to her going to a special school and I worry that she will forget what she has learned."

We will continue to:

- create models for integration in practice in order to involve the Ministry of Education in this movement
- lobby local and national government
- enlist support both inside and outside Romania
- promote positive publicity through articles in the TREBUIE! magazine, seminars, use of photos, etc
- encourage parents to take their children out to the park and other public places in order to change attitudes and promote inclusion in the community.

"TREBUIE!'s main strength is the desire and determination to build a decent future for disabled children."

Strategic plan to focus the work of LSMHP, 2000–2004

We have identified four key areas of work:

- **Our work with young people** – recognising that this is a developing area of our work that is expanding
- **Our work with parents and young children** – recognising that this is the core of our work among disabled people in Lesotho
- **Our organisation** – recognising that we need to build on the existing structure of the organisation
- **Our networking partnerships** – recognising that while networking partnerships appear to offer our organisation a great deal, sometimes we fail to gain from or give to the partnership.

1. Young people (adults)

Our Youth Development Programme centres around the need to empower young adults with skills so that they may realise their full potential and achieve full rights in society. They need opportunities to be engaged in meaningful activities; to build confidence; to reduce their dependency on families; to be involved in decision-making; and to be provided with opportunities to advocate for their rights.

The present situation is that a small group of people meet weekly in Maseru. They have been involved in a number of activities over the last two years, including a drama project. Some time has been allocated to

discussing issues that affect the young people and recently visits to places of work have taken place in an effort to raise awareness.

Challenges we face

We recognise that often young people have not been involved in activities and many have not been provided with opportunities for formal education. Those who enter formal education tend not to receive the attention and care they require. These young people have often been taken advantage of by being employed without pay. As LSMHP developed, priority was placed on working with young children and parents. These young children have now grown up and need attention. Parents are also beginning to realise that these young adults need as much care and attention as young children.

As our work with young people develops, we are often finding that we need to take on their parents' role. Parents do not appear to want to develop their children in the way they did when they were young. The young people are not mixing with other youth of the same age. If they did, it would be an ideal opportunity for awareness-raising. The existing Maseru group is an ageing group and the age range is expanding rapidly. It may soon be appropriate to divide it into two smaller age-related groups. The programme itself suffers from a lack of skilled and appropriately trained staff; a shortage of volunteer help; problems of ownership; and a lack of long-term funding. The programme has expanded to two of the existing LSMHP branches, where there is a need for more development and training to take place.

Attempts have been made to integrate some of the young people into vocational training establishments, but often these are not meeting their needs. There is a lack of initial assessment skills and overall support for this establishments programme.

Our strategy

- continue with the training of young people in advocacy, sports and self-awareness
- provide appropriate training and awareness for professionals to understand the problems faced by these young people
- network with other young people's organisations
- include an awareness of young people within all aspects of our work

-
- provide training and resources to the adults working with young people.

2. Parents and young children

Working with parents and young children was the basis for forming the organisation. Our work centres around the need to empower parents with skills, so that they may realise the need to advocate for their children's rights (Parent Empowerment Programme). This includes identifying services, assisting with skills' provision to enable them to provide a better quality of life for their children, and initiating parent-to-parent support.

Presently our work in this area involves the strengthening of our branches by the provision of more direct support and training. We train parents in disability issues and advocacy; make suggestions for improving the quality of life; focus on branch leadership; and work with a network of 13 branches. Branches are encouraged to form sub-branches. Within this work there is an emphasis on the ownership of activities by parents. Opportunities to network with other organisations are encouraged and, where possible, support is offered from the secretariat. A large part of the work undertaken at grass-roots level involves raising awareness with the community at large.

Challenges we face

There are ongoing problems with the scale of poverty within the country and the lack of service provision.

Recently there has been some misunderstanding among parents about the role of the organisation. Equally there is confusion and misunderstanding over the importance of advocacy, and in many cases a lack of parental commitment to activities. Yet we have seen that where groups of parents come together they can achieve a great deal.

Our strategy

- initiate a pilot Community-Based Parent Empowerment Programme to work with and empower parents in village situations
- accelerate and focus lobbying activities
- continue with community awareness and expansion within the country
- re-emphasise the organisation's aim and objectives.

3. Our organisation

The organisation has a secretariat with staff trained in fieldwork and administration. We also have personnel from volunteer development agencies and a number of skilled volunteers within the organisation. These people are working with parents, families and children. They are also working to strengthen the management of the organisation.

Challenges we face

LSMHP was formed by parents with limited skills. As our advocacy and parent-training work developed, our 'parent group' became a 'parent organisation'. The organisation needs to be restructured to meet these changing needs. It has the capacity to develop, but is often held back by ineffective policies and procedures and a lack of management skills. At times there appears to be a low level of commitment from members and a lack of ownership by members. The geography of the country and the logistics of communication are also major problems.

Our strategy

- clarify, develop, update and simplify our constitution and working policies
- develop and promote our image so that we are attractive to funders and networking partners
- emphasise the ownership of the organisation by members
- explore the development of an office site with meeting facilities
- define our lobbying activities
- develop a policy for income-generating projects.

4. Networking and partnerships

One of our main concerns about networking opportunities is a lack of co-ordination and commitment. In many instances financial and time pressures are placed upon LSMHP's resources for little gain, often resulting in frustration when opportunities are lost or missed. We realise that the sharing of experiences from networking opportunities is often not undertaken effectively, and therefore the experience tends to be of little value.

Our strategy

- review our existing networks and participation in networking events
- define what we need from networking events
- seek ways to gain new partners and networks
- strengthen and develop our existing partnerships.

We asked the advocacy organisations if they had any advice for others. This section is a summary of what they wrote.

Advise to other advocacy organisations

From Pokhara, Nepal...

Awareness

Raise the awareness of teachers and help them learn how to teach the child so that he or she does not feel different but feels loved. Make contact with other parents and teachers to raise the awareness of neighbours, the local community and other students.

Motivation

Motivate families and communities to value education.

Attitudes

Work to change attitudes – negative attitudes remain a major barrier. They still depend a lot on caste and on the traditional jobs that people do. It is important to work on our own attitudes and on others' attitudes towards all marginalised people.

Inclusion

Place children in regular schools. This is a positive way to improve the attitudes of teachers and other students.

Meetings

Arrange meetings between professionals who work with disabled and disadvantaged people and family members. These are helpful in enabling everyone to learn from each other and to understand each other's perspectives and problems. Meetings lead to positive joint decisions and action.

From Maseru, Lesotho....

- adopt a step-by-step approach
- things have to start first with parents. Then we have to enlist the support of the chiefs and other community leaders
- we have to talk about disability among ourselves before we have the confidence to talk about it without crying. Then we can go to the family and change attitudes. Once family attitudes change, the community will also change!
- it is important to persevere.

From Queensland, Australia....

- coming together to discuss things informally gives incredible strength
- sharing experiences and clarifying a common cause enables people to work together
- workshops, guest speakers and conferences give inspiration
- bringing in people from outside is a kind of reality check and helps us to reflect and move on
- joint planning and doing things in pairs and groups strengthens individuals as well as the group
- the group reaffirms that parents are the experts on their own child
- work at developing a constructive relationship with official departments
- learn to deal with people at different levels and talk appropriately to different groups of people within the system

- always treat people with respect and be polite
- be consistent in your message and aims
- be firm, honest and positive in what you believe
- remember that parents' voices are legitimate and have great integrity
- it is important to make time for yourself and to have fun
- keep your dreams for your children – they give you the passion that drives the work towards inclusion.

From Timisoara, Romania....

- finding a common goal for parents is most important at the start
- it is very important for the organisation to have a vision to work towards
- it is important not to be discouraged by small things
- agreed values and philosophy will help with this but these should be regularly reviewed and updated
- have a strong belief in what you are doing.

From Bucharest, Romania....

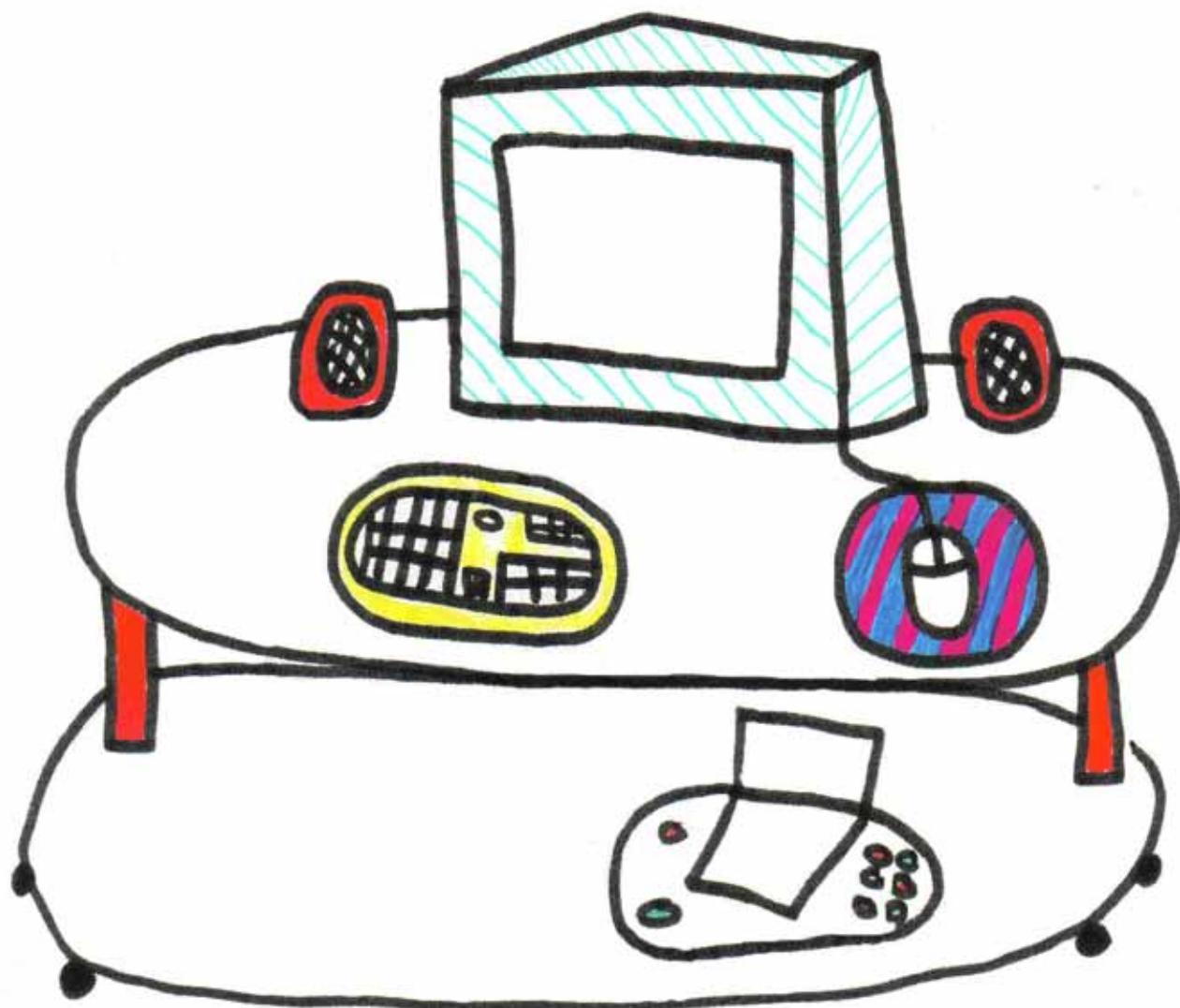
It is hard work and involves a great deal of effort, but the satisfactions are also great. A child, who yesterday could not even eat with a spoon, today has learned to read – even if it has taken more time than it takes other children.



Notes

Part 4

Resource Materials



In the following pages you can find out more about: the key international documents affecting marginalised children and their family members; organisations working in the field of advocacy; and relevant books, videos and website references.

International documentation

The UN Convention on the Rights of the Child (UNCRC)

Article 2: Non-discrimination

This states clearly that every Article applies equally, and without exception, to all children, irrespective of race, colour, sex... disability, birth or other status.

All children have the right to education, to survival and development, to know and be cared for by their families, to participate in leisure activities, and to have their opinions heard.

Articles 28 and 29: Quality education for all

This says that all children have a right to education. It is the state's responsibility to provide free primary education to all, drawing on international assistance where necessary to ensure this right. Styles of school discipline should reflect the child's human dignity.

Unfortunately there is no specific mention of the importance of early intervention and preschool education which can help reduce the impact of impairments.

Article 23: Disabled children's rights

Article 23 relates specifically to disabled children. It highlights the fact that some disabled children may have specific individual needs. It thereby reinforces Article 2, by providing more specific information about the support that disabled children might need in order to have equal access to the same rights as other children.

Unfortunately, the special mention that is made of disabled children in Article 23 of the UNCRC has many weaknesses. It refers to concepts such as “special care” and “special needs” without defining them. Other phrases such as “subject to available resources” and “education...in a manner conducive to the child’s achieving the fullest possible social integration” could be used to justify educating children in residential special schools, rather than in their neighbourhood school, as specified in the Salamanca Statement (see below).

*The UN Convention on the Rights of the Child is available from UNICEF offices or from their website:
www.unicef.org*

UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993)

Rule 6: Education

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 educational system.

Also

Parent groups and organisations of persons with disabilities should be involved in the education process at all levels.

*The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities is available from the website:
www.un.org/esa/socdev/enable/dissre00.htm*

*Disabled Person's Unit
Dept for Policy Co-ordination and Sustainable Development
United Nations
Room DC2-1302
New York
NY 10017, USA*

Salamanca Statement and Framework for Action (1994)

We believe and proclaim that

- every child has a fundamental right to education, and must be given the opportunity to achieve and maintain an acceptable level of learning
- every child has unique characteristics, interests, abilities and learning needs
- education systems should be designed and educational programmes implemented to take into account the wide diversity of these characteristics and needs
- those who have special educational needs must have access to regular schools which should accommodate them within a child-centred pedagogy capable of meeting these needs
- regular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all; moreover, they provide an effective education to the majority of children and improve the efficiency and ultimately the cost-effectiveness of the entire education system.

Salamanca Statement, Paragraph 2

We call upon all governments and urge them to encourage and facilitate the participation of parents, communities and organisations of persons with disabilities in the planning and decision-making processes concerning provision for special educational needs.

Salamanca Statement, Paragraph 3

The guiding principle that informs this Framework is that

schools should accommodate all children regardless of their physical, intellectual, social and emotional, linguistic or other conditions. This should include disabled and gifted children, street and working children, children from remote and nomadic populations, children from linguistic, ethnic or religious minorities and children from other disadvantaged or marginalised areas or groups.

Introduction to Framework, Paragraph 3

The Framework acknowledges the differences in learning needs and speeds which are evident in all classrooms all over the world

Special needs education... assumes that human differences are normal and that learning must accordingly be adapted to the needs of the child rather than the child fitted to pre-ordained assumptions regarding the pace and nature of the learning process.

Introduction to Framework, Paragraph 4

The Salamanca Statement and Framework for Action is available from the website:
www.unesco.org

UNESCO
Combatting Exclusion in Education
7 Place de Fontenoy
75352 Paris 07 SP
France

Useful publications

Further information about all the following publications and videos can be obtained from EENET. The direct contact details of suppliers have been included, where appropriate.

Gender and Disability: Women's Experiences in the Middle East

Abu-Habib, L (1997)

This publication features case studies from Lebanon, Yemen, and Palestine.

*Oxfam Publishing
BEBC
PO Box 1496
Parkstone
Dorset, BH12 3YD
UK
E-mail: publish@oxfam.org.uk*

Co-operation between Families and Schools: Parent Power Experience in Lebanon

Farah, F (2000)

This short chapter tells the story of an initiative taken by the Lebanese Down's Syndrome Association to promote educational inclusion. It stresses the importance of partnership between parents and school staff, and the benefits for all children of including disabled children in their local schools.

The chapter can be found in *Meeting Special and Diverse Educational Needs: Making Inclusive Education a Reality*. Savolainen, H, Kokkola, H and Alasutari, H, 2000,(eds).

Available free from:
Ministry of Foreign Affairs of Finland
The Department of International Development Co-operation
PO Box 176
00161 Helsinki
Finland

Disabled Children in a Society at War: A Casebook from Bosnia

Hastie, R (1997)

This book describes the move from institutional care to integration in the community in a post-communist society.

Oxfam Publishing
(as above)

Disabled Children's Rights – a practical guide

Jones, H (2001)

This simply written manual includes a simplified version of the UN Convention on the Rights of the Child and a summary of the UN Standard Rules. It also has a useful checklist for including disability issues in child rights programming. It comes with a CD-ROM entitled 'Disabled Children's Rights: examples of good practice and violations from around the world'.

Save the Children Sweden
SE 107 88
Stockholm
Sweden
Fax: +46 (0)8 698 90 20
E-mail: info@rb.se
Web: www.rb.se

It is Our World Too: A Report on the Lives of Disabled Children for the UN General Assembly Special Session on Children

Lansdown, G (2001)

This is a simply written report which has a section on inclusive education.

Disability Awareness in Action (DAA)
11 Belgrave Road
London SW1V 1RB
UK
Fax: +44 (0)20 7821 9539
E-mail: info@daa.org.uk
Web: www.daaa.org.uk

A Bundle of Sticks: Family-based organizations in developing countries

McConkey, R (2001)
Unpublished paper

This is a very useful summary of the way in which parents associations are developing in the North ('developed countries') and the South ('developing countries'), with particular reference to learning difficulties.

School of Health Sciences
University of Ulster, Newtownabbey
BT37 0QB
Northern Ireland

Telling Our Own Stories: Reflections on Family Life in a Disabling World

Murray, P and Penman, J (eds) (2000)

Let Our Children Be...a collection of stories

Murray, P and Penman, J (eds) (1996)

Two inspiring publications. Although set in the context of the UK, they are simply written and accessible to a wider audience. Many of the stories describe experiences of inclusion in, and exclusion from, education.

ibk initiatives
Aizlewood's Mill
Nursery Street
Sheffield, S3 8GG
Tel: +44 (0)114 282 3489
Web: www.ibkinitiatives.com

Where there is a will, there is a way. Training guidelines for parents and professionals in creating 'a society for all'

Parent Mobilisation Resource Group and DICAG (2000)

Funded by NFU, Norway . Copies of this short document are available from EENET.

Gender and Disability – the implications for caregivers of disabled children in an informal urban community in South Africa

Philpott, S (1995)

This short article reviews the gender issues related to the care of disabled children in income-poor families.

Disability Equality in the Classroom

Rieser, R and Mason, M (1992)

Parents of children with disabilities requested the writing of this very informative publication. It has been written by disability equality trainers who have a great deal of experience of promoting inclusive education. Although it is based on UK experience, it is very easy to adapt to other situations.

Altogether Better: From 'Special Needs' to Equality in Education

Rieser, R and Mason, M (1994)

This video training pack promotes the creation of school systems that value difference and therefore enhance the educational environment for everyone. Produced by Charity Projects.

*Disability Equality in Education
Unit 4Q Leroy House
436 Essex Road
London N1 3QP
UK
Fax: +44 (0)207 354 3372
E-mail: info@diseed.org.uk*

In Our Own Words: Disability and Integration in Morocco

Save the Children UK (1995)

This is the story of disability services in Morocco from the point of view of the young people themselves. Educational integration is discussed in some detail.

*Save the Children UK Publications
c/o Plymbridge Distributors Ltd
Estover Road
Plymouth PL6 7PY
UK
E-mail: orders@plymbridge.com*

Parents' Wishes: a collection of educational wishes parents have for their physically disabled children

Tisdall, R (1997)

This is a report of a study conducted in Nepal by the National Special Education Programme, a component of the Basic Primary Education Programme. Detailed individual case studies are included in the report.

Report of a Parents Conference in Malawi

(1999)

This was the first conference for parents of deaf children to be held in Africa.

*Available from:
Miss Doreen Woodford
Administrator
Deaf Africa Fund
Chapel Cottage
7 King Street
Much Wenlock TF13 6BL
UK*

Items available on EENET's website

www.eenet.org.uk

Parents as Trainers of Families, Professionals and Communities

(1999)

This is a training course developed by the Lesotho Society of Mentally Handicapped Persons (LSMHP). It is available in English and Spanish.

Bridging the Gap between Parents and Professionals

McConkey, R (1999)

This is a workshop guide which will help others prepare similar training events to the one described in 'Empowerment' on p33.

Parents' Stories

Hard copies are also available from EENET's office for readers who do not have access to the Internet.

APASENTH	Asian Parents' Association for Special Educational Needs in Tower Hamlets, London, UK
DICAG	Disabled Children's Action Group, South Africa
LSMHP	<i>Achieving Change: Parents Training Parents.</i> The Lesotho Society of Mentally Handicapped Persons (Parents and Families).
CBRS	<i>Let's Work Together: Community Based Action for Inclusion.</i> Community Based Rehabilitation Service, Nepal
QPPD	<i>Striving for Inclusive Education for All.</i> Queensland Parents for People with a Disability, Australia
SARPV	<i>Setting up a Parents' Group.</i> Social Assistance and Rehabilitation for the Physically Vulnerable, Bangladesh
Speranta	Timisoara, Romania
TREBUIE!	An organisation for children and adults with special needs, Bucharest, Romania

Innovations in Developing Countries for People with Disabilities

O'Toole, B and McConkey, R (eds) (1995)
Lisieux Hall Publications in Association with AIFO–Italy (Associazione Italiana Amici di Raoul Follereau)

This book is now out of print and permission has been obtained from the publisher to reproduce it on EENET's website. The following chapters are directly relevant to work with parents and family members:

3. *Fostering Parental Involvement* (in India), Pramila Balasundaram
8. *Mobilising Parents of Children With Disabilities in Jamaica and the English-Speaking Caribbean*, Gerlin Bean and Marigold J Thorburn
9. *Fostering the Formation of Parents Associations* (internationally), Pal Skogmo
12. *Mothers of Disabled Children as CBR workers* (Philippines), Barney McGlade and Rita Aquino

Videos

Preparing Teachers for Inclusion (1996)

This is a video training manual produced in Lesotho. It is available from EENET at a cost of £30 to Northern organisations, and free of charge to South-based and South-funded organisations. The video contains over 250 minutes of footage from Lesotho and it deals with a wide range of issues related to inclusion, including the role of parents. The video manual is available from EENET's website.

Building on Ability (2000)

This video was produced by the Community Based Rehabilitation Service (CBRS), Nepal. It gives an insight into the day-to-day lives of disabled children supported by CBRS in Nepal. There is a focus on educational inclusion.

See p.110 for CBRS contact details.

Including All Children
(2001)

This video is set in the UK context, but it has a wide appeal. It focuses on educational inclusion and the role of parent organisations.
The video is 17 minutes long and costs £10

*Parents for Inclusion (PI)
Unit 2, 70 South Lambeth Road
London SW8 1RL
UK*
*E-mail: info@parentsforinclusion.org
Web: www.parentsforinclusion.org*

R esource organisations

Asian Parents' Association for Special Educational Needs in Tower Hamlets

APASENTH
The Brady Centre
192-196 Hanbury Street
Tower Hamlets
London E1 5HU
UK
Tel: +44 (0)207 375 0554
Fax: +44 (0)207 377 0450

Centre for Studies on Inclusive Education

The Centre for Studies on Inclusive Education (CSIE) provides information about inclusion and related issues. It is a registered charity and its work is based on human rights principles.

The Centre for Studies on Inclusive Education (CSIE)
Room 2S, 203 S Block
Frenchay Campus
Coldharbour Lane
Bristol
BS16 1QU
UK
Tel: +44 (0)117 344 4007
Fax: +44 (0)117 344 4005
Web: www.inclusion.org.uk

Child-to-Child Trust

The Child-to-Child Trust co-ordinates a worldwide network of health and education workers in over 60 countries. The Trust is an independent charity, based in the University of London, which designs and distributes health education materials and advises on the implementation of Child-to-Child projects.

Child-to-Child Trust
Institute of Education
20 Bedford Way
London WC1H 0AL
UK
Tel: +44 (0)207 612 6648/9
Fax: +44 (0)207 612 6645
E-mail: ccenquiries@ioe.ac.uk
Web: www.child-to-child.org

Community Based Rehabilitation Service – CBRS

CBRS
Naya Bazaar
PO Box 293
Pokhara
Nepal
E-mail: cbrs@mail.com.np

Deaf Africa Fund

The Deaf Africa Fund (DAF) exists to meet the needs of deaf children and their families in income-poor countries. One of those needs is for parents to have access to up-to-date information and opportunities to meet other parents, both within their own country and in other countries.

Miss Doreen Woodford
Administrator
Deaf Africa Fund
Chapel Cottage
7 King Street
Much Wenlock TF13 6BL,
UK

Disabled Children's Action Group – DICAG

DICAG
16 Broad Street
Wynberg
7800 Cape Town
South Africa
Tel: +27 (0)21 797 5977
Fax: +27 (0)21 797 5077
E-mail: dicag@iafrica.com

Inclusion International

Inclusion International was formerly called the International League of Societies for Persons with Mental Handicap – ILSMH. It is a human rights and advocacy organisation, which works closely with the United Nations. It has 173 member organisations in 109 countries (1998) and works closely with regional Inclusion International groups.

Inclusion International
c/o The Rix Centre
Room 1001
University of East London
4-6 University Way
Docklands Campus
London E16 2RD
Tel :+44(0)20 8223 7709
Fax :+44(0)20 8223 7411
E-mail: info@inclusion.international.org
Web: www.inclusion.international.org

Lesotho Society of Mentally Handicapped Persons – LSMHP

LSMHP
PO Box 9204
Maseru 100
Lesotho
Fax: +266 322462
E-mail: lsmhp@lesoff.co.za

National Deaf Children's Society

The National Deaf Children's Society (NDCS) was founded in 1944 by parents firmly committed to improving educational opportunities for their deaf children. Education remains at the forefront of the Society's work as it strives to improve the rights and needs of all deaf children and young people. In recent years it has played a small role in supporting work with deaf children in other countries, such as Jordan and Cuba.

The National Deaf Children's Society
15 Dufferin Street
London EC1Y 8UR
UK
Fax: +44 (0)20 7251 5020
E-mail: ndcs@ndcs.org.uk
Web: www.ndcs.org.uk

Norsk Forbund for Utviklingshemmede (NFU)

NFU is the Norwegian Association for Persons with Developmental Disabilities. NFU is a national advocacy organisation working for the full inclusion of persons with developmental disabilities. NFU also supports sister organisations in Lesotho, South Africa, Tanzania, Zimbabwe and Jamaica.

NFU
Postboks 8954 Youngstorget
0028 Oslo
Norway
Tel: +47 22 39 60 50
Fax: +47 22 39 60 60
Email: post@nfunorge.org
Web: www.nfunorge.org

Queensland Parents for People with a Disability – QPPD

QPPD
PO Box 470
Paddington
Queensland 4064
Australia
E-mail: qppd@qppd.org
Web: www.qppd.org

Save the Children Sweden (SC S)

SC S works for the rights of children by developing knowledge about children's conditions and needs, sponsoring practical development and support programmes and disseminating the experience gained, and by influencing public opinion and decision-makers.

Save the Children Sweden
SE 107 88
Stockholm
Sweden
Fax: +46 (0)8 698 90 20
E-mail: info@rb.se
Web: www.rb.se

Save the Children UK (SC UK)

Save the Children is the UK's leading international children's charity. SC UK works in more than 70 countries on emergency relief and long-term development initiatives. SC UK draws on practical experience to influence policy and practices to achieve lasting benefits and the realisation of rights for children within their communities.

Save the Children UK
1 St John's Lane
London EC1M 4AR
UK
Tel: +44 (0)20 7012 6400
Fax: +44 (0)20 7012 6963
Web: www.savethechildren.org.uk

Social Assistance and Rehabilitation for the Physically Vulnerable – SARPV

SARPV
1/2 Block-G, Kazi Nazrul Islam Road
Lalmatia
Dhaka-1207
Bangladesh
E-mail: shaque@bd.drik.net

Speranta

Societatea Română Speranta
Str Fagului Nr 17
Timisoara 1900
Romania
Email: societatearomanasperanta@yahoo.com

TREBUIE!

TREBUIE!
Str Linei nr 37
Block 6c, 5cA, E74, Ap 10
Sector 6
Bucharest
Romania
E-mail: florentina@dnt.ro

“ For us the concept of segregation is completely unjustifiable. It is morally offensive. It contradicts any notion of civil liberties and human rights – whoever it is done to, wherever it appears. Segregation is damaging for our children, for our families and for our communities. We do not want our children to be sent to segregated schools or any other form of segregated provision. We do not want our children and our families to be damaged in this way. Our communities should not be impoverished by the loss of our children.

Our children are the ones who teach us about the issues. They give us the opportunities to learn and understand. They give us determination and confidence. They give us hope and courage. They show us how it can be. Our children are teaching us to be their allies. ”

*Pippa Murray and Jill Penman
Parents with Attitude, Sheffield, UK*

Family Action for Inclusion in Education celebrates the stories of family-based advocacy organisations which have helped to transform education systems in southern Africa, South Asia, Europe and Australia. Quotations from family and community members provide the reader with valuable insights into the activities, thoughts and feelings of parents involved in fighting for the inclusion of their disabled children.

In countries of the South the challenge of providing education for all children, including those who are marginalised, is not being met. Disabled children are among the economically poorest groups in society, and the most marginalised from education.

This guide has been written for family and community members who may feel isolated and want to form a support group, or advocacy organisation, to challenge exclusion. It will also be of interest to those interested in promoting more inclusive practices in education, such as teachers, teacher educators, policy makers and consumer organisations.



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c/o Educational Support and Inclusion
School of Education
The University of Manchester
Oxford Road
Manchester M13 9PL
UK

Tel: +44(0)161 275 3711
Fax: +44(0)161 275 3548
Email: info@eenet.org.uk
Web: www.eenet.org.uk