Lesotho Society of Mentally Handicapped Persons, Parents and Families (LSMHP)

"We realise that the way we treated our children at first may have made their disability worse. We wish we had known then what we know now."

# 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 head teacher 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 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 head teacher and threatened to report him to the Minister of Education! The head teacher 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 head teacher 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!

# How we began

We founded the Lesotho Society of Mentally Handicapped Persons (LSMHP) in 1992. The Ministry of Education already had a policy on integrated education and had started a pilot project in ten schools, one school in each of the ten districts in Lesotho, and in 1993 a survey found that 17% of children in primary school had a disability. However, the project was limited to those schools. We decided not to wait for the results of the pilot but to take action ourselves to promote the development of more inclusive practices.

LSMHP has a very clear rights-based approach and philosophy. Our aim is to represent the rights and needs of children and adults with mental disabilities. Our goal is to set up branches all over the country so that children and adults with mental disabilities throughout Lesotho will be supported and represented.

By 1999 LSMHP had 12 branches in 6 out of the 10 districts and a total of about 700 members. 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.

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.

All persons with mental disabilities and their families can become members, and since 1994, membership was 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 Views of Education and Inclusion

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

The word for "inclusion" in Sesotho, our language, 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.

**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.**

Teachers were reluctant to accept children with mental disabilities at first, but now they even teach other children 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, children with mental disabilities who had access to education were made to repeat the same class over and over. Now children are able to move within the school and can earn promotion from one class to another like any other child!

"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!"

# Our Strengths and Strategies

"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."

Through meeting, sharing and learning together, parents have become aware that how they treated their children at the start may have aggravated their disability. They expressed regret that that they did not know this earlier.

## Empowered parents

LSMHP parents have now identified what they mean by an "empowered" parent: An empowered parent is a parent who:

1. knows the rights of her/his child with disability;
2. knows about existing facilities and services for his/her child in the community and how to use them to benefit the child;
3. knows what is good and what is wrong for the child and is confident enough to say "No" to what is wrong;
4. can guide and gain the good will of other parents and the local community in helping and supporting children with disabilities;
5. explores national laws and policies to find out how they protect and serve her/his own child and other children with disabilities;
6. knows the channels whereby to seek justice for her/his child;
7. 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;
8. has the courage to promote 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;
9. understands that a child with disability deserves the same dignity as other children;
10. understands the concept of human rights and social justice and that disability is not an individual issue but is a social issue;
11. can contribute equally to the resolution of her/his child's problems; who would not just take instruction from professionals;
12. understands that getting rid of barriers to the inclusion of disabled children does not depend only on an individual but on the community.

## Parents as Trainers

As parents in the organisation became empowered through meeting each other and discussing the issues that faced them, they identified their own needs for training. As a result the "Parents as Trainers" initiative was set up. This training was a crucial milestone in LSMHP's development and progress.

A group of key parents, known as 'resource parents', were trained to be trainers and to pass on their knowledge and skills to other branch members of LSMHP. The aim of the training 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

A one-week workshop was led by 3 outside consultants with the help of local personnel. Most of the workshop participants were relatives of disabled people and 6 were community workers. Only one participant, a community worker, was male. A manual or Workshop Guide and a video "Bridging the Gap between Parents and Professionals" have been produced to help others prepare similar training events.

The emphasis was on learning by doing. We learned how to:

* Make introductions;
* Talk about our experiences as parents;
* Ask and answer questions;
* Present information;
* Make and use visual aids such as charts and posters; \* Lead discussions;
* Use video;
* Organise and evaluate training.

On the last day of the workshop 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 by workshop participants. Feedback from the professionals acknowledged that they now realised the value of what parents have to say.

So resource parents had a live experience of organising, preparing and delivering a training event. We were also invited to draw up an action plan of the training we expected to set up in our local area within the next 6 months. We were offered some on-going support in carrying out these plans by local tutors and one of the consultants.

Resource parents practice the suggestions offered in the training with their own children and also offer training to 20 other parents. This includes the following topic areas:

* What is disability: both the medical and social causes of disability are taught and we explain that it is "normal to have a child with a disability";
* Activities of Daily Living skills (ADL): 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;
* Enrollment 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.

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.

The training was successful in a variety of ways and led to some very positive outcomes which included:

* Membership of LSMHP doubled and new branches were formed;
* An increase in the number of disabled children enrolled in mainstream schools;
* Some parents set up income generating projects and included teenagers with disabilities;
* Children with disabilities are being integrated into sports;
* Integration was promoted at all levels; disabled adults are involved in community development projects such as road and dam building.

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

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

## Advocacy

LSMHP informs and lobbies relevant government departments and non- governmental organisations (NGOs) about the rights and needs of people with disablilities, especially children and adults with mental disabilities. There is an increasing emphasis on encouraging parents to work on changing systems and attitudes.

## Awareness-raising

Community gatherings are held by LSMHP in different parts of the country. These are attended by: chiefs, priests, health workers, parents and school children. We use role-play and singing to get the message across. The key to our work in raising awareness is to "harness the energy in the community" and use the valuable human resources within the community. During the process families of children and adults with disabilities are identified. Subsequent visits are made to the families to empower them and make them more aware of their rights and responsibilities.

## Formation of branches

After these local meetings local branches are formed by parents and families. Training is then offered at branch level.

## Early Intervention

There is no national system for early identification and provision of services. However LSMHP offers support and training to the parents of young disabled children and works closely with Scott Hospital's CBR Project on early identification. Parents play an active part in the programme. They are trained by the hospital to identify needs, how to help their own child and how to help and advise other parents. Unfortunately this service is limited to the families and

LSMHP members who live within the catchment area of the hospital. LSMHP established its own early intervention programme in Maseru, after realizing that the Scott Hospital service was limited to those in the catchment area. Children are brought to Maseru by their parents for training in activities of daily living (ADL). LSMHP has also embarked on research to find out more about the situation and requirements of families needing help with early intervention. At the same time, LSMHP is active in raising awareness in government departments, such as Health and Social Welfare, of the need for early identification and services for young children and their families.

## Placing of children in inclusive education

Members of LSMHP visit local pre-school facilities, primary schools and vocational institutions to seek placement for children with disabilities. After admission regular follow up visits are made to monitor their progress.

## Youth Development Programme

Young adults meet weekly in Maseru, the capital, and in 3 other branches, to discuss their problems in life and how to tackle them. They also meet with other youth groups. One of their activities has been to develop a drama on human rights. More recently visits have been arranged to various business and commercial ventures in an effort to raise awareness of their needs. Attempts have been made to integrate some of the young people into vocational training establishments, but often these do not meet their needs. So far staff lack initial assessment skills and the programmes lack support.

Our work with young people aims to empower them with skills so that they may realise their full potential and achieve full rights in society. They need to be provided with opportunities to be engaged in meaningful activities, to build confidence and reduce dependency on families. They need to be involved in decision-making and to be provided with opportunities to advocate for their rights.

We recognise that often young people have not been involved in activities, many have not been provided with opportunities for formal education and those who do enter formal education often do not receive the attention and care that 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 to receive attention. Parents are now 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 the parent's 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, which could be an ideal opportunity for awareness-raising amongst young people. The existing Maseru group is an ageing group and the age range is expanding rapidly.

# Our Difficulties

## Exclusion

The main difficulty now is that of severely disabled children who are still not accepted in schools at all! It is very difficult for parents to teach their child at home. Children learn better in the classroom environment.

## Poverty

The major issue is one of poverty. This is the greatest difficulty for many parents who need financial help to enable their children to access education.

## Attitudes

Social attitudes remain another major problem. It takes a very long time to change attitudes towards our children. Parents come together to solve the problems we face. We cannot do it alone. We started by changing attitudes at home. Our own and our family's attitudes had to be changed first. Then we worked on changing attitudes in our village and our community. Finally we approached the schools.

We did not go straight to the schools at the start! We came to LSMHP for assistance and received counselling and advice. At first we hoped our children could be cured. Later we realised that a cure was not possible - but we would get support.

# Our Future Plans

## Parents and young children

* 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.

## Young people

* Continue with the training of young people in skills and activities: advocacy, sports, self awareness;
* Provide appropriate training and awareness for professionals to understand the problems that young people face;
* Establish networks with other young people's organisations in order to both raise awareness and to share experiences;
* Examine the structure of the existing groups and when necessary establish new groups that are 'age based';
* Include an awareness of young people within all aspects of our work;
* Provide training and resources to the adults working with young people to ensure that the programme becomes properly owned by both the organisation and the young people.

## Our organisation

* Define roles and provide specific skills training to key volunteers within the organization;
* 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 role and ownership of organisation by members;
* Explore the development of a 'site' to provide office accommodation and meeting facilities.

## Networking and Partnerships

* Review our existing networks, our participation in networking events and the selection of networkers;
* Define what we need from networking events in order that we achieve something from each opportunity;
* Seek ways to gain new partners and networks;
* Develop a policy for income generating projects.

"The government should dedicate a budget specifically for the inclusion of disabled people".

## Our messages for other parent organisations

\* Adopt a "step by step" approach; \* We have to talk about disability first amongst ourselves to 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! \* Things have to start first with parents. Then we have to enlist the support of the chiefs and other community leaders; \* It is important to persevere.

# The social context

Lesotho is a small mountainous, land-locked country surrounded by South Africa with which its economy is inextricably linked. More than a third of the male workforce seeks employment in South Africa. The population, mainly Basotho people, is estimated at 2 million. The majority of the people are Christian and the language is Sesotho. Much of the country's energy, and about a quarter of its food, has to be imported as only a small percentage (10%) of the land is suitable for arable farming.

Educational provision in Lesotho is a joint venture between the Government, churches and the community. Primary education is compulsory for seven years from age six. Secondary school, beginning at age 12 lasts for up to five years. Nearly 75% children enroll for primary school but only a quarter enroll at secondary school. More girls than boys attend primary school as many boys are needed to work as goat and cattle herders. Vocational and technical education has increased in recent years.

## Time line

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| **1991** | Ministry of Education sets up pilot project for disabled children  |
| **1992** | LSMHP founded for parents of children with mental handicap |
| **1993** | LSMHP registered |
| **1994** | LSMHP became part of the Parent Mobilisation Support group (PMRG) in Africa Contract and Funding from Norwegian Association for Mentally Retarded (NFU) |
| **1997** | Constitution revised to include parents of children with other disabilities Training for Resource Parents as trainers |
| **1999** | LSMHP has 12 branches and about 700 members. |

Sources: An EENET member met with a group of LSMHP parent members and a number of young disabled people in 1999. In addition, a number of LSMHP documents and articles by one of the society's founding parents, Palesa Mphohle. Save the Children Fund have provided additional information.

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**Reference:**
**Title:** Achieving Change: Parents training parents
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