DOWN SYNDROME SOUTH AFRICA

"Break the Barrier, Strengthen the Township' Project

MY DAD TAKE'S PART IN THE FAMILY







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FOREWORD & ACKNOWLEDGEMENT

Down Syndrome South Africa has had a longstanding cooperation with LEV since 2004. During this time several projects have been successfully implemented. The idea behind the current project *"Break the Barrier – Strengthen the Township"* project was created when I, together with staff members of Landsforeningen LEV held a meeting in June 2010.

DSSA and its branches/support groups have been actively working in the townships in South Africa by developing and supporting Outreach groups. However DSSA has identified other townships as areas of concern in so far as it does not have sufficient capacity to reach these townships and the families living in these areas.

DSSA together with Landsforeningen LEV realised that it is possible to include and develop a project working in these townships by developing Self Help Groups (SHG) guidelines, conduct training, establishing SHG and develop an advocacy strategy to be used by these groups. The project will run from 1st July 2011 to 31st January 2014.

Down Syndrome South Africa is extremely grateful to Landsforeningen LEV (Denmark) and the Danish Foreign Ministry for funding this very important project *"Break the Barrier – Strengthen the Township"* which focuses on the development of Self Help Groups in the targeted townships in South Africa and empowering parents of children with intellectual disabilities and Self Advocates.

As part of this project "My Dad Takes Part in the Family" (male role) activity. These guidelines have been developed for "training the trainer" (TOT) to use in giving examples of best practice for the SHG. It has been developed in such a manner that trainers will be able to assist families and parents of children with intellectual disabilities in getting fathers to participate in the SHG.

I wish you all the best success in implementing the guidelines for the betterment of individuals with intellectual disabilities and their families.

Yours truly,

Vanessa dos Santos



ACRONYMS

AIDS	-	Acquired Immune Deficiency Syndrome
DSSA	-	Down Syndrome South Africa
HIV	-	Human Immune Virus
ID	-	Intellectual Disability
LEV	-	Landsforeningen LEV
NPO	-	Non Profit Organisation
PWID	-	People with Intellectual Disabilities
SHG	-	Self Help Groups
ТОТ	-	Trainer of Trainer

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1. INTRODUCTION

The purpose of these guidelines is to assist the DSSA SHG's to carry out the project successfully. This manual offers guidance through the process with practical activities and examples. It is our intention to make sure that you understand our goals and assist you in reaching that.

These guidelines on "*My Dad Takes Part in the Family*" will assist the SHG's to encourage participation from the fathers of children with intellectual disabilities in the groups. Furthermore, these guidelines can be copied so that it can be used by other SHG's of people with intellectual disabilities should they feel the need. Experience shows that once fathers have seen the material they feel confident to do be more involved and spread the word by mouth. The fathers will participate more in the SHG and set good examples in the townships. The DSSA SHG's will be trained in how to include fathers to be more involved in these groups.

The advocacy work is at many levels in the project from raising awareness among the parents, towards local authorities and service providers at local and towards national levels. Thus duty bearers at all levels generally become more aware of their responsibilities and obligations for people with intellectual disabilities. An increased awareness among parents about their rights and duties will be spread to other parents, as it will be a big change at the grassroots level that the father suddenly takes his child with him to the market, church or school. The changed behaviour in the fathers will most likely have a spillover effect on others.

These guidelines were developed by DSSA and should be used as a tool to include fathers in the SHG's in South Africa in the targeted townships in South Africa.



These pictures do not imply that all fathers behave in this manner

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2. DOWN SYNDROME SOUTH AFRICA

2.1 Down Syndrome South Africa

Down Syndrome South Africa (DSSA) is a NPO and was formed in 1986 as the national umbrella body and parent advocacy organization and lobby group for the constitutional rights of persons with Down syndrome and other intellectual disabilities.

DSSA currently has 12 regional branches/support/outreach groups throughout the country who provide services and support to people with Down syndrome and other intellectual disabilities and their families.

2.2 Aims and vision of DSSA

DSSA extends its care, support and services to children and adults from all backgrounds who are intellectually disabled, as well as those with multiple disabilities and with global developmental delay.

DSSA is committed to finding ways to improve the quality of life of all persons with Down syndrome and other intellectual disabilities promoting the fact that they have the right to live with independence, dignity and security as valued adults and full citizens in our society.

2.2.1 Ongoing mission is:

To bring South Africa in line with world trends in the field of Down syndrome, and to become leaders in some aspects;

See to it that the UN Convention on the Rights of Person with Disabilities are recognized and honoured in all spheres of life.

2.3 Key focus area:

- The establishment of parent support groups and community development projects in the impoverished areas of our county;
- The empowerment of families of persons with intellectual disabilities through the dissemination of information, by means of printed materials, workshops and talks;
- The establishment of a forceful parent lobby and advocacy group which has been able to bring about changes in national and provincial policy in favour of persons with intellectual disability;
- The raising of public awareness in both urban and rural areas specifically around 21st March (World Down Syndrome Day) and 20th October (National Down Syndrome Day) annually;
- To promote the inclusion of people with Down syndrome and other intellectual disabilities into various sectors in the community.

3. TARGETED TOWNSHIPS

Target Townships

3.1 The areas where the "Break the Barrier – Strengthen the Township" and Self Help Groups have been developed are:

PROVINCE	BRANCH NAME	TOWNSHIP
Gauteng	Gauteng DSA	Orange Farm
Gauteng	Pretoria DSA	Attridgeville
Kwazulu Natal	Kwazulu Natal DSA	Ugu District
Eastern Cape	Amothole DSA	Mdantsane
Eastern Cape	Port Elizabeth DS SG	Motherwell
Free State	Free State DSA	Mangaung
Western Cape	Western Cape DSA	Mfuleni
Western Cape	Support Cape DSA	Fisantekraal
Limpopo	Limpopo DSA	Letaba
Mpumalanga	Witbank Outreach	Kwa-Guqa
Northern Cape	Kimberly Outreach	Greenpoint
North West	Potchefstroom Outreach	Ikageng

3.2 Background of the Self Help Groups

The SHG have been set up in the 12 areas indicated above and has now grown to include Mafikeng and Nelspruit. Training of the trainers took place during September 2011. There after the SHG guidelines were printed and distributed to these groups. The first SHG were then formed using the SHG guidelines manual (Please always refer to this manual for assistance). Since then more groups in these provinces have been developed and the number of members has increased. Further training has taken place with these groups in the establishment and development of them.

3.2.1 The purpose of the Self Help Groups is to:

- Bring parents and family of children with intellectual disabilities living in close proximity together to provide one another support;
- Empower parents and people wit intellectual disabilities in townships with tools to develop SHG's;
- Give and exchange accurate, unbiased information about intellectual disabilities and effective ways to cope with it;
- Provide emotional connection with parents that feel isolated from friends and extended families and to help normalise some parents and people with intellectual disabilities feelings and an opportunity to release their powerful emotions;

3. TARGETED TOWNSHIPS

- Provide practical solutions to shared problems by exchanging ideas and coping strategies;
- Advocate and claim the rights for people with learning disabilities in their townships;
- Enable parents to identify and meet their own needs;
- **4** To create awareness amongst community members in their townships.

3.2.2 Advantages of these groups:

Leads to reduced anxiety, decreases psychological distress, depression and feelings of pain and increased mood, self-image and the ability to cope and feeling in control; Parents are empowered to speak out in a safe platform to express their feelings; Parents develop new skills and abilities to stand up for their rights;

No "professional" or outside involvement thus giving them some sense of ownership; Broadening the network base.

3.2.3 Disadvantages of these groups:

Negative experiences may heighten anxiety; Responsibility can lie with a few key members; Some members may dominate.

3.3 "My Dad" and the Self Help Groups

The important of fathers in these SHG is recognised by DSSA, which has resulted in the activity "My Dad Takes Part in the Family".



4. MY DAD TAKES PART IN THE FAMILY

4.1 Main problem

The main problem that this activity will address is the fact that in South Africa some fathers due to various reasons are not always involved with their intellectual disabled child and the family. Very often this exclusion is self-inflicted. (Fathers choose to exclude themselves from the family).

Furthermore fathers experience grief, which is often unrecognised and unexpressed, with no support from professionals or employers. This failure of recognising the need for inclusion is made worse through the fathers' belief that they When Asina was six months old her parents noticed that she wasn't growing properly and was developing problems with her vision and hearing. Her father blamed her mother for giving birth to a disabled child and her mother felt obliged to hide Asina from their neighbours. Taken from Able Child Africa.

Sadly this story is a reality of which many families experience.

are the stronger of the sexes and therefore need to be strong for the mother of the child. This leads to the fathers giving more support to the mother than the other way around.

Fathers are usually the breadwinners of the family and therefore often cannot fully participate in the added pressure and activities of raising a child with a disability. The pressure of also having added financial responsibilities found that some fathers worked longer hours in order to provide which means that many fathers miss out of family appointments with health care professionals and as a result do not always understand their child's disability and health condition.

Studies have shown that fathers have reported working longer hours than usual and consuming more alcohol more frequently as a way of dealing with their own emotional trauma. Fathers of low-income families tend to be affected more by the birth of their disabled child and spend less hours with their child than those of higher income.

Research findings:

■ Nearly half of fathers (43%) keep the fact that they have a disabled child a secret from their boss.

- Six out of 10 (61%) think mothers are treated differently from fathers, with 84% feeling excluded at coffee mornings, social clubs and support groups.
- Four out of 10 feel sad or lonely as a result of caring for a disabled child.
- Nearly two-thirds (63%) say they cannot easily talk to others when times are difficult.



5. When a disabled baby is born into the family

When a baby is born and diagnosed with a disability this often comes as a shock for the entire family. This can sometimes feel like a death. A death of a dream. The father may have had dreams of his son being a soccer star or becoming a doctor. At this time the various stages of grief come into play. These are:

- Denial "I feel fine". "This cannot be happening to me". "The baby looks fine...the doctor must be wrong"
- Anger "I am cross, why has this happened to me". It is not fair!".
- Bargaining "if only..."
- Depression "I feel so sad"
- Acceptance "it's okay, I may as well prepare for this".

These stages do not always follow in the order above, however for some fathers stay at the 'Denial' stage longer than mothers and find it difficult moving past the 'Anger' stage. This can also result in blaming the mother for the child being disabled. Things such as *"we don't have this is our family...it must be from you and your side of the family"*. Fathers have been known to leave the family believing that it is the mothers fault that the child has been born disabled.

Many dads find it easier to accept that their daughter has a disability than they would if it were a son. Fathers may also experience levels of failure, guilt and reduced self-esteem. They may also be embarrassed by the physical appearance or lack of development of their disabled child. However some (older) fathers have reported that their disabled child has had a positive effect on their belief system.



"When I hold Jessica, I look into her eyes wanting to see that same sweet, smiling baby that used to crawl to me. The truth is that baby is gone. I now have another baby, one who will be my baby for the rest of her life". Excerpt from Uncommon Fathers.



6. **DEALING WITH GRIEF**

Think of your situation and write down?

How did this make you feel?

What did you do in this situation?

Did it help and if so how?

How do you think you can help others in the same situation?

Do you need more information or assistance, if so what?

7. IMPACT OF THE FATHER

It is very common for fathers to talk about disabled children in very positive terms. However a child's disability can still have a substantial impact on the father. Some of the literature has found that fathers and mothers of children with disabilities report high levels of stress. It should not be assumed that all fathers of disabled children experience stress or that such stress is directly attributable to their child's disability, but studies comparing parents of disabled and non-disabled children have found the former had much higher levels of child-related stress and depression.

Uncertainty about how best to meet their child's needs, their child's limitations and how they will develop, their education, and where the family can go for practical and emotional support are all sources of stress for fathers and mothers.

Concerns about the child being accepted socially have also been found to be a greater cause for fathers stress than mothers of children with intellectual disability.

Some studies have found that most fathers thought their reaction to their child disability was the same as their partner's, but about one fifth felt that their response was more "practical and rational" in order to support than their partners. Men's social networks tend to offer less encouragement and accessible support than women's, with the result that fathers rely much more on their partner for emotional support.

Activity 1: Journey to self-awareness and growth.

Divide into groups of four or five and discuss the following topic:

- a) What does it feel like to be a father of a disabled child
- b) What has it been like?
- c) Has it been a different experience for you compared to your nondisabled children?

"Dads are sparks that push. Dads are often pushy about moving their child on; mums have had it all the time and may get despondent". A dad

8. THE NEEDS OF FATHERS

8.1 What are the needs of fathers?

Like any parent, when you find out that your child has a disability the first thing you are likely to look for is information. Most fathers feel this is the most important issue, but most soon learn that it is vital not to forget the child in their search for information.

A lack of information about available services and benefits can lead to financial hardship, fathers report being concerned about the costs of child care: the loss of income from the mother remaining at home. They also tend to be overlooked by support services, even when they make every effort to be involved with their children and are the primary carers or equal carers with the mothers.

"I spent hours looking for information on the internet. In the end I realised I was torturing myself. My time is better spent with my children".

Understanding the experiences and addressing the needs of fathers of children with intellectual disabilities are important for a number of reasons:

- Many fathers of children with learning disabilities are very involved in their children's lives and their contribution is a valuable resource for their partners and for their children;
- Some fathers want high level of involvement but find this hard to achieve, mainly due to work commitments, but also for other reasons such as divorce or separation or their own ill health;
- Recognising, encouraging and sustaining this involvement through policies and practices within education, health and social services, as well as within employment will have lifelong implications for children with learning disabilities;
- Fathers are not always recognized as parent carers by support services for children and families, employers and GPs and often there is an assumption that mothers are the primary carers: this can lead to feelings of exclusion, additional stress and may contribute to family breakdown.
- Fathers often have more limited support than mothers and see their partner as an important source of support: this has implications for single or separated fathers and also for mothers who may experience this as an additional burden;

8. NEEDS OF FATHERS CONT...

- Families with a child with disabilities are often able to have only one earner which puts considerable pressure on the working partner, usually the father, to maximize their income. The need to earn can be exacerbated by the additional costs related to their child's disability such as the need for equipment and adaptations. Fathers can be torn between the need to earn and the desire or need to provide care and support;
- Employers do not always recognise the fathers as parent carers and therefore do not provide them with the information and support they need to combine paid employment and caring roles. Fathers who are unaware or who find it difficult to find information in their workplace on their rights as a parent of a child with disabilities to seek parental leave, flexi time or other benefits will inevitably find themselves in a weaker position without sufficient guidance to enforce their rights;
- This lack of support and information can lead to fathers making decisions that result in a loss of employment, training and career opportunities which in turn result in a loss of income for the family over many years, including in retirement. This reduction of income has implications for the life opportunities to children with disabilities and the rest of their family;
- Fathers' struggle to maintain their work and their involvement in their children's care and support can lead to increased physical and mental ill-health. This can become a cycle as ill-health can, in turn reduce men's capacity to earn and provide care for and support to their children and partner;
- Some fathers are also providing support to their partners who are experiencing physical or mental ill-health that is often related to the additional responsibilities of having a child with disabilities;
- The impact on fathers' health often goes unrecognised by GPs and other health workers: fathers are rarely offered preventive health care or support to promote emotional well-being.

Can you think of any other needs of fathers to achieve the involvement they would like and feel confident in their parental role?.

9. DISCUSSIONS ABOUT RESPONSIBLE FATHERHOOD



Fathers have been identified as "hard to reach", "the invisible parent" and "underground fathers" – men who are involved in the lives of their children; but refuse to participate as fathers in formal systems. What is keeping men from being more involved and what it would take to become more involved?

- b) Unlike mothers, fathers tend to seek support almost entirely from their partner or spouse rather than friends or family;_____
- c) Often dealing with how people react to your child's disability can be one of the difficult issues. What is the best way when dealing with other people's reactions?
- d) What services do you mostly use and for what?_____
- e) Describe your expectations or the difficulty that you anticipate regarding your child's future?
- f) What are you doing to ensure your child's welfare in the future?_____

10. INVOLVING FATHERS IN EDUCATION

10.1 Fathers' Involvement in Education

Families are considered the primary context of children's development; children perform better at school and have fewer discipline problems when their parents are actively involved in their learning. But over the years "parent involvement" often meant mothers' involvement.

In early learning programmes and schools, and within the family itself, it has been assumed often that mothers have the primary responsibility for encouraging the children's learning and development. These assumptions miss the importance of fathers' involvement.

High involvement by the father can make a positive difference for children's learning, at the early childhood level, high involvement refers to the frequency with which parents interact with their young children, such as how often they read, tell stories, and sing and play with their children. These experiences contribute to children's language and literacy development.

- The most common involvement activity in which fathers' participate is a general school meeting, such as back to school open day.
- Most fathers do participate in at least some of the activities in their children's schools. But parents tend to divide the task of involvement between them.
- The involvement of one parent in a two-parent home motivates the other parent to be involved. However, dads are less likely than moms to attend a parent-teacher forum or volunteer at school.
- Parental involvement in schools is closely linked to parental involvement at home. Higher father involvement is particularly related to the number of activities the family participates in with their children, the frequency with which the parents helps with homework and whether a parent regularly participates in a community service activity.

10.INVOLVING FATHERS IN EDUCATION

10.2 Why are fathers not more involved in their children's education?

Strategies that strengthen family involvement in education must take into account barriers that confront families, schools and communities.

- Getting fathers into the school building. Some schools, preschools and childcare programmes don't have family –friendly environments and are not organized to work with families. When parents are invited to schools, fathers are less likely on average to respond to these invitations for involvement. Why? Part of the reason is that parents assume that such invitations are for mothers only. Though incorrect, the assumption is understandable; in our society, the word *parent* in the school context and others has often been interpreted to mean *mother*. Moreover some parents believe schooling should be left to the education experts and family's role is one of caring and nurturing outside of school.
- Institutional practices. Institutional practices and barriers imposed by the workplace are ranked as the most important reasons for fathers' low levels of involvement. Paternity leave is the most frequently discussed means of enhancing paternal involvement, even though some research indicates that flexi time schedules would be of greater value in encouraging fathers' involvement.
- Language and cultural barriers. Some fathers feel uncomfortable to come to school and interact with educators because they lack, or may believe they lack the necessary communication skills.
- Disconnected community based organisations. Community based organisations that attract families with children such as churches and childcare centres, are often disconnected from schools. They operate their own programmes and are missed opportunities to link families with schools.
- **Education of parents.** Parents' education is a more significant factor than family income in whether or not they will be involved in their children's education.
- Lack of time. Today's workers are increasingly asked to do more with less, and thus work longer hours. Dual-career families may face scheduling conflicts and have less control over work hours, further aggravating the balancing act of work and family.
- Not knowing what to do. Parents generally, and fathers specifically, may not know how to assist their children with their education.



10. INVOLVING FATHERS IN EDUCATION

There are strategies to reduce obstacles to fathers' involvement in education. To help dads warm up and get involved with their children means to convince them of the significance of small, very simple interactions with their children—interactions that may seem very insignificant to the dads, but mean a great deal to their children.

It is important to remember up front that both sensitivity and self-confidence are greater than any specific skills in-patient in paternal behavior and influence. Sensitivity is critical to both involvement and closeness. The closeness of father-child relationship is a crucial determinant of the dad's impact on the child's development and adjustments. Developing sensitivity enables a dad to evaluate his child's signals or needs, and respond to them appropriately.

10.3 What fathers can do at home, at school and in the community.



Fathers can initiate or participate in activities that help their children succeed.

	Break into groups and discuss and write down some of the activities that
you think yo	u could At home
	At School
	In the Community

11. STRATEGIES TO IMPROVE FATHERS INVOLVEMENT IN EDUCATION

At home, fathers can:

- Read with their children. The ability to read well is known to be one of the most critical skills a child needs to be successful. The father can stimulate his child's imagination by telling stories using a picture book.
- Establish a daily routine. Fathers can set time for home work, chores and other activities.
- Make the most of bedtime. Bedtime is a terrific opportunity for fathers to connect with their children. For one thing, the audience is definitely captive. At bedtime a father can enrich a child's life merely by recounting what he did during the day. Every moment he spends and every word he says builds a relationship with his child.

At school and other childcare development programmes, fathers can:

- ♣ Participate in efforts to keep their children's schools or childcare centres safe.
- 4 Attend parent-teacher forums and other school events.
- Volunteer at school and help with school programme needs like painting and repairing school property.
- ↓ Visit their school and meet the educators.
- Join the parent-teacher association or other parent groups at their child's school or childcare centre. At meetings, they can make their voices heard regarding their concerns and ideas for school improvements.

In the community, fathers can:

- 4 Play or coach a game or sport they like with their children on a regular basis.
- Become involved in community activities which enhance their children.
- Take time for family outings to places such as cinemas, music concerts and sport events.
- **4** Use their community resources and recreational facilities.

There are many other issues that fathers could also get involved in other than education. Can you think of some?:

One of the most important things a father can do for his disabled child is to stand up and speak for their rights. Since many children with intellectual disabilities cannot stand up and speak for themselves we as parents/fathers need to do so. This leads us to Advocacy and Rights.

12. ADVOCACY AND HUMAN RIGHTS

12.1 Advocacy and Human Rights

All people are different and yet we all are entitled to the same human rights. Human rights are what people need to live with dignity and to enjoy freedom. All people are entitled to human rights, this includes people with disabilities, even those with multiple or significant disabilities. Very often people with disabilities are discriminated against and their human rights are denied. This is why we need to advocate (*speak up for our rights*), to be treated the same as everyone else. Rights describe the way people should be treated and what they are allowed to do. Some rights are called laws. Government writes these laws. People with disabilities should always be included when laws are written. The United Nations has also written a convention for people with disabilities. This is called the Convention on the Rights of Persons with Disabilities (CRPD). When someone denies disabled people access to services or treats them unequally they could be breaking the law.

The preamble of the CRPD recognises the "diversity *(the differences)* of persons with disabilities", and highlights the "need to promote and protect the human rights of all persons with disabilities, including those who require more intensive support".

Some examples that people with disabilities have the right to:

- Be treated as equals;
- Go to school and to choose where they go to school;
- Choose where and with whom they live;
- Go to work and choose where they work and what they do;
- Have relationships;
- Get married and have children;
- Vote;
- Open and hold a bank account;

Many people with disabilities are often not able to do any of this because there have been people who have stopped them.



As a father write down some examples of your rights not being met.

12. ADVOCACY AND HUMAN RIGHTS

12.2 Responsibilities

With rights come responsibilities. This means that you need to think about how your actions affect other people. They need to be treated with respect and equally. Furthermore people with disabilities *(self advocates)* should do what they can to take care of themselves and be responsible for their actions.

Example: People with disabilities have the right to work and employment (Article 27 of the United Nations Convention on the Rights of Persons with Disabilities). Even though people with disabilities have this right it does not mean that any company/organisation must give them a job. People with disabilities must take responsibilities to ensure that they are employable.

12.3 What is Advocacy?

Advocacy is a human rights approach that can influence law, policy and or other decisions that can be important. It can be directed at government level, institutions or individuals.

12.4 Why should we advocate?

By advocating for our rights we ensure that we are not discriminated against. It also ensures that we will be treated equally and that all laws are the same for people with disabilities.

12.5 What should we be advocating for?

There are many issues that self-advocates could be advocating for. For instance when laws don't include people with disabilities, or for when laws are in place but not being implemented.

Example.

A parent of child with Down syndrome applies for a child to attend the local primary school but is refused admittance because he has Down syndrome. The school feels the child will slow the other children down in their learning. They also fear that the child will not be able to cope with the learning in the school. The law clearly states that schools may not discriminate against any child regardless of whether they have a disability or not. This is a reason to advocate for the child's right to be admitted to the school.

Activity: Divide into groups and discuss what you could be advocating for and how you would plan it how you would do it. Time 15 min. Report back and role play.

13. FATHER GROUPS AND THE FRIENDLY ENVIRONMENT

Most father groups come about as a result of belonging to the local association. If your branch/support group aims to promote the importance of father and male involvement, and the fathers group here are some ideas to use as a checklist will help to ensure that you have the building blocks of success.

- ♣ Assets of fathers are emphasized, not their deficits.
- Budget indicates that fathers are a priority.
- 4 Curricula and education materials respect the range of fathers being served.
- Diverse staff reflects the population using the service.
- Environment clearly states that dads and men in families are welcome here.
- Father-child bond is emphasized and encouraged.
- **4** Gender-neutral forms, policies and procedures are employed.
- Hands-on learning experiences are components of many activities.
- Importance of fathers is promoted but not at the expense of mothers.
- ✤ Journals, magazines and reading materials reflect the interests of dads, too.
- **4** Knowledgeable men are recruited to address sensitive concerns of fathers.
- Language is respectful and affirming of all parents and children.
- **4** Marketing plan invites many faces of fathers and promotes their full involvement.
- **4** Needs of fathers influence the programme growth and development.
- Outreach staff recruited in locations that all types fathers frequent.
- Paternal and maternal parenting styles are recognized and respected.
- 4 Quality evaluation tools and procedures that respect fathers are in place.
- Recognise and reduce barriers that limit father involvement.
- 4 Understand wide range of fathers' physical and mental health concerns.
- ↓ Values that promote gender reconciliation are recognised.
- ✤ Women's' perspectives be considered in the planning of programmes.
- Excellent advisory council and speakers are in place.
- Young fathers are offered services
- Zealous attitude prevails that we are all in this together.

(Fatherhood needs to be offered status and equality. As expectations of father involvement in child-rearing change, society must ask itself if there are adjustments to support this intrinsically valuable redefinition. It is time that men started to challenge assumptions that the nurturing of children has nothing to do with them. Our children need their male role models as well as the female ones.)

14. STARTING A FATHERS NETWORK

There are numerous fatherhood programmes that strive to meet the various needs of the many different fathers and families. Fathers who share a common bond of some kind will often form a support group. The idea of the group is to link with other fathers to share concerns and frustrations, to find ideas for being a better dad in your circumstances and create a network of people who can be a support to one another.

Generally, fathers' support groups tend to be informal and kind of freewheeling, in the beginning. Some fathers may decide to hang out together and share experiences. Then others are added as the word spreads and the groups meet regularly and take some form of structure. But as they mature, there tends to be more structure and formality.

14.1 Lessons learned in starting a programme involving the fathers.

- Involve fathers wherever a programme or agency involves the mother. The exclusion of fathers, even when they wanted to be involved is repeatedly mentioned in discussions.
- Have men lead fatherhood programmes. A father-led, father's only group gives them the safety and ability to open up about their doubts, fears and other emotions. Have strong male leadership; use men to recruit and facilitate the programme.
- Include the mothers in complementary group activities. The good relationship with the child's mother is also important. The fatherhood programme should not merely replicate the single gender focus of many of the current social services programmes serving mothers and children.
- Let the fathers help determine the type of activities. Build programmes around stated needs of the men in the programme. If possible have developmentally appropriate father-child activities.
- Provide resources, education and information. Facilitate group leadership skills, including group norms, handling differences, listening and confidentiality.
- Never let costs or money get in the way of father involvement.
- Be flexible in scheduling; find places and times where men can attend meetings and programmes.

14. STARTING A FATHERS NETWORK Cont...

- Have meetings in places that are friendly, easygoing, nonclinical and relaxed.
- Laugh, have fun through social times and activities (both for men only and with their families).
- **4** Know that numbers alone have little to do with the programme success.
- Always spend time to "celebrate success" ("bragging rights"). The men need unlimited opportunities to "brag about their kids and the value they have in their children's lives.
- Provide food and snacks. "Feed them and they will come". (Yes food makes a difference).

14.2 Activities you can do to ensure that your group is active:

Raise awareness in the community to make people understand your disabled child; Let them know that they too have feeling and also want to be included in the community with respect;

Reduce the isolation of children with disabilities and their families

Promote parental skills and responsibilities to their child with an intellectual disability, etc.

These are just some of the many examples - Can you think of more?

14.3 Remember:

- These are guidelines are just that guidelines. What works for one group may not work the same for your group. Do what works best for your group.
- The main aim of the group is to bring people with the same challenges or similar issues as others.
- This is a volunteer group and all must work together and support one another to make it work and to make a difference in your community.
- Invite community leaders to some of your meetings. You can also invite experts in the field every so often to address the parents.
- Join other disability groups such as the provincial disability alliance or local disability alliance if there is one.

14.4 Congratulations, you have now completed the process..... This however is only the beginning and not the end. Where do you see yourself or the group in a year's time? The group will continue to grow if you all pull together and work together.