



Including All Children!

Guidelines for parents of
children with disabilities

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Chapter 1:

Our approach to disability and impairment

Why we need to think about the words we use

Words and pictures can help us to understand what's real and they can also affect how those around us think and act.

When we refer to someone "with disabilities", we shouldn't speak as if there is a "problem" with that person. Instead we should recognise that any problems related to someone's disability may be caused by the *other* people's attitudes or the way we deal with impairments in the community.

Using negative language about impairments and disabilities strongly affects children. It is important to think about the language we commonly use to describe people, and check the meanings of our words and the ideas associated with them.

These guidelines do not state which terms we should or should not use. Rather, they are intended to make us all more aware, and to increase the respect shown to children with disabilities and those who care for them.

Language influences the way children think of themselves or others, and negative language can affect how a disabled child develops emotionally. It can affect a child's opinion of their own worth and abilities. Positive language can encourage a child to succeed beyond the limits created by their physical condition.

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1. Our approach to disability and impairment

Most people want to respect others yet we may not realise how the language we use stops others from being accepted.



We 'inherit' language and often do not give it much thought. However, we do have a choice and we can decide which words we use to say what we mean.

The main thing to remember is to use words that respect the dignity, rights and diversity of people with disabilities. Parents, brothers and sisters, and others in the community – especially teachers – must ask speakers not to “label” people with impairments, often with hurtful phrases or words.

Words connected with disability

Before we look at the different terms in Chapter 2, think about how you use the word ‘disability’. We should treat ‘impairment’ and ‘disability’ as two separate issues that people may face.

Impairments include physical, sensory, intellectual or mental long-term or short-term conditions. Examples include lacking part of, or all of, an arm, hand or leg, or having a limb or organ that does not work properly.

Disability is the result of the barriers placed by society on people with impairments. Impairments can become disabilities as result of the person’s environment including the attitudinal, institutional, or economic and political barriers to their participation in society.

1. Our approach to disability and impairment

These barriers stop people taking part in society and include:

- attitudes;
- leaving out people who have impairments;
- not allowing access to school or other community activities; and
- physical barriers to accessing buildings or moving about.

It is society that creates disabilities for people who have limits of different kinds.

Function or functional limitations describes what activities someone cannot do and what they can do despite having an impairment which affects part of their body. While impairments may affect a person's ability to perform certain tasks, it does not mean she is not able to excel in different activities. However, she might have limitations on performing specific tasks. For example, a person might not be able to walk but this does not mean she cannot solve difficult intellectual concepts.

We should also realise that someone with an impairment may not necessarily be limited in their activities.

Our view on disabilities

World Vision International views disabilities as a complex socio-cultural and economic issue with political consequences rather than only a medical or individual issue. We support the development of communities that will allow people – regardless of their disabilities – to live fully. We aim to change the stereotypical view of a person with impairments which often results in violations of the person's rights to participate in school, community activities, meetings, leisure, or employment, as well as forming a family.

Everyone has things they can and can't do; many people have impairments; and everyone is special!

How to speak to a child or adult living with impairments:

Rule 1 Treat them with dignity and respect. Put the person first, and do not label them by always pointing out:

- their condition (for example, limited movement or learning difficulty);
- the cause of their condition (for example, polio or Down's syndrome); or
- the aids they use (for example, a wheelchair or glasses), e.g. "the girl in the wheelchair".

Acknowledge that all persons have the same basic needs as well as different other needs. All have different abilities and inabilities. For example, someone who uses eye-glasses would not want to be referred as "eyeglasses", "someone with special needs" or "differently abled". To refer to someone as a "person with special needs" would put the person in a separate category and therefore could discriminate or isolate her from the mainstream population. In the same way, everyone is special and gifted, and has different abilities and inabilities. Do not label a person as having "special needs or gifts", or as "differently able".

Rule 2 Do not make assumptions about the person's feelings. For example, we can't always know if someone who lost a leg due to traffic accident is still suffering or feeling scarred by their impairment, or if they have overcome these feelings. We cannot assume what kind of challenges each person might face or how she might feel about it. These challenges and feelings depend on different things. For example, the person who has lost a leg due to a traffic accident might feel different about it than a person who was born with this condition. Moreover, the life experiences and individuality of each person can affect the situation and her feelings.

Rule 3 Don't label the person as a 'victim'. Someone who was recently injured by a landmine may be considered a victim. But it is an insult to continue to see them as a victim all their life. They might have overcome the distress and discrimination they face because of their impairment. It is important to recognize the efforts that an individual may make after the accident to challenge her disability and use her abilities.

Rule 4 Do not assume that all people with special conditions or impairments are unhealthy or in need of medical support. We cannot use the terms "healthy child" to contrast with a child who has an impairment! A child who has difficulty walking or seeing may be perfectly healthy. On the other hand, don't assume that able-bodied children are healthy – many able-bodied people have health problems as well. Impairments are not infectious. Any ideas that you can 'catch' these conditions from a disabled person are due to ignorance.



Rule 5 Remember that what is 'normal' for you may not be 'normal' for other people. "Norms" are created by us depending on our personal, socio-cultural, economic and political values. Because we all come from different personal and cultural backgrounds, we look and behave differently. Therefore, *each one of us can help in making our societies more inclusive for all people* regardless of where they fall within the existing norms.

Rule 6 Use respectful language. The word "defect" is unfortunately sometimes used in referring to a person with an impairment in some parts of the world. A machine can have a defect but a person cannot be "defective", as they still have the potential to change and develop. In the same manner, no one is incomplete or complete, while everyone is complete and incomplete. We are all fearfully and wonderfully made and able to change.

Rule 7 Use simple language. It is clearer to say someone has "difficulty walking" (or hearing, seeing, and so on) than saying they have a "mobility impairment". Always look for simple terms such as "he has difficulty getting around" rather than labelling the person. By using simple, respectful and clear language, people will always understand what you are saying. Be attentive to the cultural context and use simple but respectful language.

Chapter 2:

Definitions

In this chapter we briefly give the main terminologies and definitions that help parents and communities learn, understand and use respectful disabilities language.

It is important that we follow rules 1 to 7 in Chapter 1 when we speak to people with disabilities. The DPOs in your community or country should be able to guide you. It is good to ask people with disabilities in your culture how they would like people to describe them.

Basic terms

Activity limitations: This is the term we use to describe the difficulties someone may have carrying out certain activities. For example, a person may not be able to read regular print because of impairment with their sight.

Disability: A disability is the result of the barriers placed by society on people with impairments. People with impairments often can't play a full part in society because of the attitude of others, or because of problems with the environment. An example of a disability would be a child with cerebral palsy who wants to sing with others but is left out because people think she would not be able to sing in tune with the group. We treat 'disability' as a problem with society and 'impairment' as a medical or individual issue. This helps us to clearly see the two issues a person may be facing and also helps us to take the necessary actions to find solutions.

Disability organisations: These are local, national or international organisations which are managed by people who are not necessarily disabled, working for people with disabilities. Community-based teacher and parent support groups are examples of disability organisations.

Disabled people's organisations (DPOs): These are local, national or international organisations which are managed by people with disabilities, for people with disabilities. Disabled Persons International (Canada) is an example of a DPO.

Impairment: An impairment is a physical, sensory, intellectual or mental long-term or short-term condition. Examples of impairments include:

- having part or all of an arm, leg, foot or hand missing; or
- having a limb or organ that does not work properly.

"Mental illness", "mental disability" or "mental retardation": Again, because we work in different social contexts, we use 'mental illness' or 'mental disability'. However, many people with disabilities avoid 'mental retardation' though it is still used by medical professionals

Other terms we hear or read

Activity limitations: These are the difficulties someone has when they try to do certain activities. Remember though that limitations can be reduced. *Examples:* A person who cannot see to read regular print can be helped with Braille texts. A home or school with smooth firm surfaces and a ramp for wheelchairs and wider doors greatly helps a person who uses a wheelchair. The kitchen, bed and bathroom can all be adapted to help increase activity levels of children with disabilities.

Acute: Sudden and short-lived. An acute illness starts suddenly and lasts a short time.

Adaptation: These are changes to a situation that help a child. Adaptations may include seats with pads or straps that support a child's body. "Adaptive equipment" can be made or bought through organizations.

Arthritis: This is a medical condition that causes pain and inflammation in one or several joints of the body, such as the knee, elbow or hip.

2. Definitions

- Ataxia:** This medical condition causes difficulty with balance and coordination.
- Atrophy:** A condition which causes the organs and muscles to waste away. It can be caused by not enough food, by ageing or muscles not being used. See also **dystrophy**.
- Behaviour:** This is the way a person does things or reacts to situations. It is the word used to describe how a child acts or relates to his social or physical surroundings.
- Chronic:** Ongoing. A chronic illness is one that lasts a long time or goes away and comes back.
- Contracture:** This is a medical condition which reduces the amount of movement in a joint, often due to the muscles or tendons being shortened.
- Dystrophy:** This is a muscle weakness that gradually gets worse. It is caused by a problem in the muscles themselves. See also **atrophy**.
- Environmental factors of disability:** These are the physical, social and cultural elements which affect how people live and carry out activities. See also Chapter 3: Parenting, culture and child development.
- Evaluation:** Observations and study to see how well something is working. The findings are used to identify problems and make changes so things work better. An example is a leg brace that may need regular evaluation as a child grows.
- Hereditary:** Familial or biological and genetically passed down. If something is hereditary, it is passed down from one generation to another, through the father or mother (or sometimes both) to their children.
- Hygiene:** Actions or practices to prevent disease, especially through cleanliness.
- Infantile:** Concerning babies or young children.

Infection: This is a sickness caused by germs (for example, bacteria or a virus). Some infections are 'local' and affect only part of the body, while some are 'general' where all the body is affected. Infections can be passed from person to person, by animals or insects, or from mother to child before or during birth.

Multiple disability: If someone is described as having multiple disability, it means they have several disabilities, often both physical and mental.

“Nothing About Us Without Us” Principle: This is the rule used by Disabled Persons' Organizations, to make sure that people with disabilities are included in the development of any action, laws, programmes or policies that affect them.

Paralysis: Muscle weakness or loss of ability to move part or all of the body.

Paraplegia: Paralysis or loss of movement in both legs, caused by disease or injury to the spinal cord (back).

Parenting: Taking care of a child. Good parenting includes talking clearly to children so they understand what they are expected to do, consistently rewarding them for good behaviour and helping them to develop new skills. It also includes making sure they are safe, and protecting them.

Prevention: This includes a wide range of actions that can help avoid disabilities. Long-term prevention includes reduction of poverty and poor living conditions. Short-term prevention includes actions such as vaccinations (polio, for example), breast feeding babies to avoid infections of many kinds; avoiding medicines during pregnancy; obtaining natural vitamins through food, eating well and consuming iodized salt during pregnancy. Preventing accidents is very important too – see chapter 'Safety and Protection'.

Progressive: Steadily changing. A progressive illness, for example muscular dystrophy, steadily becomes worse.

2. Definitions

- Prosthesis:** An artificial limb (arm or leg) or other part of the body. **Prosthetics** is the craft of making prostheses.
- Rehabilitation:** The process of helping a disabled person to manage better at home and in the community after illness.
- Retarded:** Slow to develop. A mentally retarded child does not learn as quickly or remember as well as other children.
- Rights-based approach to disabilities:** Policies and behaviour that include children with disabilities, based on the *United Nations Convention on the Rights of the Child* (CRC) and the *United Nations Convention on the Rights of Persons with Disabilities*. Children and adults with disabilities have the same rights as everyone else. These conventions try to make sure that people with disabilities are included in the development of any action, laws, programmes or policies that affect them.
- Stimulation:** Sounds, sights, activities, toys, smells, touch and all things that make a child take interest in his world. Early stimulation helps a baby develop his first responses and skills.
- Therapy:** “treatment”. **Physical therapy** or “physiotherapy” improves position, movement, strength, balance and control of the body. **Occupational therapy** helps a disabled person learn useful or enjoyable activities. A child can become his own best therapist sometimes, if shown how. The best therapies are built into daily activities such as play, work, relationships, rest and adventure.
- Transfer:** Moving from or to a wheelchair, onto a bed a chair, a toilet or the floor. Transfer skills can be learned or assisted by boards, straps or other aids offered to the child. It is important to encourage the person with impairments to move independently.
- Virus:** Germs that are smaller than bacteria and cause a different range of illnesses, and spread more easily. Most viruses are not killed by antibiotics.

Chapter 3:

Parenting, culture and child development

Parents of a child with disabilities often spend much time wondering why their child is 'different'. Scientists and child specialists who study development and behaviour think that both environmental and biological factors have a role to play. They do not agree on what most influences a child's development or even how children develop. With so much disagreement between scientists, parents must carefully watch their child and learn what she needs for her life to develop. For example, specialists know that children can learn to speak only when old enough to do so, but even then they won't learn to speak as much if they don't meet or interact with other people. However, parents should not feel discouraged if their child hasn't spoken before she is five, for example. Children begin speaking later for many reasons.

If a child is born with permanent speech difficulties, she will need a lot of attention and, if possible, speech therapy, to support the parents' efforts to help her learn. The child with mental, hearing or speaking disabilities should receive the help she needs to achieve her full potential. Unfortunately too many parents think there is 'no point' in helping their child with disabilities to develop. Parents may receive this message from their own family, the community or even 'specialists'.

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Culture and parents' attitudes towards impairments

Different peoples hold different beliefs, values, attitudes and behaviour and they pass these on to their children.

'Culture' is shared information about a community's history, beliefs and skills which is passed on from generation to generation. There are wide differences in culture between countries and even within different areas of the same country. Language is one part of culture, the food you eat is another – but how we raise our children (parenting) is probably the most important aspect of culture that makes us who we are. Different peoples hold different beliefs, values, attitudes and behaviour and they pass these on to their children. The way families include and support their children with physical or mental impairments is part of their culture. Questioning cultural practices is important, to be sure your child's rights are protected – *you as a parent are the child's key to the world*. You can help the community understand that disabilities are everyone's concern, not just the child's and her parents'.

Culture affects the physical environment in important ways – the type of house we live in, the natural and built surroundings. As children are brought up, they are influenced by these factors which also, in turn, influence their development. Friendly environments help children feel their family and community cares: a ramp for the wheelchair to enter the school or home, railings to hold onto for children with difficulties walking or seeing, are examples.

It is important to remember that culture is 'two-way': parents are as influenced by their children as the children are influenced by their parents. *Parenthood is also about developing and adapting. Parents learn new skills from caring for their children*. Of course children's genes are passed along by their biological parents; genes determine the form of our bodies and some of our behaviour. Yet the family can do much to influence the genes it passes on to its children. The most important influence on the development of babies and young children is the quality of the care they receive.

Photo: M.E. Chatwin



Parents can help

Parents and family can encourage their child with disabilities, even very young, to get involved in daily activities.

One example: Babies usually begin to crawl sometime during the second six months of life (if they are not constantly 'swaddled' or bound). If babies are allowed to move around the floor, they might first creep on their stomachs, then rock on their hands and knees, then start to crawl. These developments are 'continuous processes' – they follow one after another. Children with an impairment might take longer to learn, but they continuously learn and make small advances. Whatever a child's capacities, the parents can help her continue to learn new things.

The most important influence on the development of babies and young children is the quality of the care they receive.

Whatever a child's capacities, the parents can help her continue to learn new things.

3. Parenting, culture and child development



Photo: J. Schenk

Adaptive equipment, appropriate toys and extra therapies are other ways to let your child with an impairment become involved and more independent.

Other types of development, for example intelligence, are more 'set', less continuous. They don't move from one stage to the next in the same way. Even so, we cannot use intelligence measured in the first few years of life to predict how intelligent someone will be when they are older. Children's intelligence can be greatly increased if parents interact with them, and by other cultural or environmental factors. Touching and interacting with your child is very important. It is important to let them participate in the family and community environment, in and outside of the home. Adaptive equipment, appropriate toys and extra therapies are other ways to let your child with an impairment become involved and more independent.

Parents, families and caregivers are the most important people to nurture children, pass on their culture and make changes in culture that will help their children.

Chapter 4:

The rights of children with disabilities

In 1948 the United Nations produced the Universal Declaration of Human Rights to protect the rights and dignity of all people. In 1989 it produced the Convention on the Rights of the Child – a legally-binding document which spells out the basic rights of children. This is a very important document for all children, including those with a disability. It means that governments have to make sure their national laws comply with international laws and they have to provide all children with the same opportunities. For example, it states that children with disabilities have the right to special care and education, so governments have to provide the services they need.

In 2006 the United Nations produced the Convention on the Rights of Persons with Disabilities – a major milestone achieved by and for disabled people. This convention is very important for everyone fighting for equality and the fair treatment of disabled people, including children.

It is very important that governments sign and ratify the document. It will, for example, make sure that children with disabilities have the right to education and health care, and it will also make sure that they have the right to take part in all aspects of life. Any government that signs up to (ratifies) this convention will have to do all they can to create a society where children are treated equally and fairly. As a non-governmental organisation (NGO), World Vision has a special role in reminding governments of their promises and responsibilities. In many cases governments are not able to deliver their promises and this is where we can help.

Governments have to make sure their national laws comply with international laws and they have to provide all children with the same opportunities.

Children with disabilities have the right to special care and education, so governments have to provide the services they need.

Special issues that need tackling

Discrimination **Discrimination** takes many forms. It can affect many people including girls, disabled children and ethnic groups. If a child is disabled, the community must take extra care to make sure they are not the victim of discrimination.

Sometimes discrimination has many layers. For example, boys and men often have a 'higher' status than girls and women. Girls with disabilities are more likely to be placed in institutions, to be abused and to be refused education. They are often not given the chance of marriage or motherhood because of prejudice and discrimination. Boys with disabilities live longer than girls since social pressure on them is far less. This can be changed by parents and communities working to change attitudes.

Here is an example of what signing up to the convention can mean to a child with a disability:

Five-year-old Lela is a little girl who was affected by polio at the age of two. She cannot walk and her behaviour has changed and she has become withdrawn. Her parents are worried about her future. There is no medical centre close by where they can receive help. Her parents, like many other families in the village, treat their sons as more important than their daughters. They have never taken Lela to see a doctor, since they do not have enough money to take all their children for medical care. The parents believe that her illness may be a punishment for some sin they have committed. Lela is not treated with a lot of care and needs help.

Since the government of the country where Lela lives has signed up to the Convention on the Rights of Persons with Disabilities, they should help Lela by, for example:

- making it possible for her to receive the medical help she needs;
- teaching her parents to recognize what their daughter's illness means and what can be done about it; and
- creating ways to change society's views that women are less worthy than men.

4. The rights of children with disabilities

In the example above, Lela has not been treated properly because she has not received health care and, in her culture, boys are treated better than girls. So, the fact that Lela is a little girl makes her face **double discrimination**. Anything that makes a child different from other children can lead to a community mistreating them. However, people and their governments can help to change the 'culture of inequalities'. For example, if women and men are given the same education and job opportunities, girls will not be seen as less valuable.

Even more discrimination and pressure is put on people who are from ethnic minorities, are refugees, or are forced to move within their own country.

Stigma A **stigma** has been defined as a mark of disgrace. A 'social stigma' is one that causes severe disapproval within society. This term is usually used to describe how society regards disability. People with disabilities may face disapproval all their lives in their communities, and even in their own families. For example, some children are over-protected or hidden within their family and rarely allowed out of the house.

Institutions Children with disabilities are too often placed in **institutions or orphanages**. In some countries parents are led to believe that their children will have a better life if they are put in special institutions. We at World Vision value the family as the foundation of our society. Reports indicate that most children in institutions are not orphans but have been placed there due to poverty, stigma or discrimination. The best place to grow and thrive is in a family, even if this means living in a home with a small group of other people or living in a small institution with personal care.

Sometimes officials and doctors encourage parents to place their child with disabilities in an institution. The reasons they give include to:

- escape stigma;
- increase the economic chances of the family; or
- give the child better care.

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Many institutions are corrupt and the staff receive payments for the disabled children in their care. This means children can be left with very little stimulation to help them develop and they have little access to real education. They are also far from their family. Placing a child for long periods of time in an institution ignores Article 23 of the Convention on the Rights of Persons with Disabilities which states that:

- people have the right to live with their families; and
- children shouldn't be separated from their parents or their wider family group because of a disability.



Photo: M.E. Chatwin

We at World Vision help disabled children stay with their immediate and extended family and seek ways to avoid children going into institutions or orphanages. We do this by:

- teaching families how to support their children at home;
- reducing the number of institutions; and
- making communities and governments aware of the rights of children with disabilities to remain in their families and communities.

World Vision promotes 'ability'

What can communities do to make sure they recognise the rights of children with disabilities? People with disabilities have the same right as others to arts, sports, games, films and other fun activities. This means that they should not only have access to theatres, museums, playgrounds and libraries, but they should be able to form groups and take part in all aspects of cultural activities.

One view of disability (called the social model of disability) does not view it as a problem that affects individual people who can be helped only by medical treatments or charity. Although it does not deny the need for medical attention, this view promotes 'ability' rather than focusing only on medical conditions and disabilities. Children with impairments must not be seen as mainly medical cases. Instead they must be seen as whole people who, like all other children, need love and the opportunity to meet other people. If they are kept away from their families or other children, they will have fewer chances to become part of their community, fewer possibilities to learn and develop their abilities, and little chance to contribute to society in the future.

We believe that children with disabilities should have the same rights as everyone else to be welcomed, respected, and educated, and to live with dignity.

A community that does not work with or support people with disabilities will never challenge its own prejudices and misunderstandings. We try to teach parents how to spot disabilities early on and how to provide good care and education so that each disabled child has the best chance to fully develop their abilities.

We believe that children with disabilities should have the same rights as everyone else to be welcomed, respected, educated and to live with dignity.

Chapter 5:

Development and disabilities: what you can do before a child is born

There are several stages that a baby (embryo) will go through before birth, and each stage needs special attention.

Before birth

Before birth the embryo floats inside its mother's womb in water called 'amniotic fluid'. It is attached by the umbilical cord to the placenta (the lining of the womb) and it uses the placenta to receive oxygen and nutrition and to pass waste and carbon dioxide back to the mother. The placenta acts as the lungs, digestive system, liver and kidneys for the baby. It also filters out some – but not all – substances that could harm it. Despite the placenta's role to protect the unborn baby, some diseases, drugs and toxins can pass through it to the developing baby.

Risks during pregnancy

Mothers should be immunized and get regular check-ups during pregnancy. If a mother does not receive proper medical care while she is pregnant, the developing baby could be at risk. Women in some cultures have so many responsibilities that they barely have time for

5. Development and disabilities: what you can do before a child is born

their children. Because pregnant women should avoid heavy chores, men and boys should take over some of them, such as growing and marketing food and washing clothes, during this important time. This will greatly help protect the health and development of the unborn child.

Sexually transmitted diseases, smallpox and measles

Sexually transmitted diseases, smallpox and measles can affect the unborn child's development. If the mother has, or is in contact with **rubella** (German measles) during the first three months of pregnancy, it might cause hearing loss, blindness or brain damage to her unborn child. She should avoid contacts with persons who have the illness during that time.

HIV virus

HIV virus also can be transmitted to the unborn child, which means that they may develop **AIDS** within two years. An expectant mother with the HIV virus should seek a health worker to get medicines to prevent transmission of the virus to her child.

Smoking

Smoking can lead to the unborn baby not receiving enough oxygen, and babies born to mothers who smoke tend to be smaller and have greater risk of cleft palate, mental retardation or hyperactivity.

Alcohol

Today the effects of **alcohol** on a pregnant mother are also known. It can lead to mental retardation, still births and pre-term (early, or premature) births. A pregnant woman should also avoid taking medicines unless it is absolutely necessary and they are prescribed by a health worker.

Toxins

Toxins (poisons) found in the air or earth can affect the development of an unborn baby. These poisons include **lead, mercury, PCB and DDT**. Radiation poses a similar risk.

Overall, the less developed an unborn baby is, the greater the risk, as they are developing very rapidly. If the baby is more developed, there is a much lower risk to many toxins.

Health watch

It is important for pregnant women, their husbands, partners, mothers and other family members to recognize sometimes there are risks that need extra care.

Warning signs before pregnancy include the following.

- The mother has had a baby within the last two years.
- The mother is less than 18 years old.
- The mother is over 35 years of age.
- The mother has already had four or more children.
- The previous baby weighed less than 2 kilograms when born.
- The mother's last birth was difficult birth or she had a Caesarian section.
- The mother has had a miscarriage, abortion or still-birth.
- The mother weighs less than 38 kilograms.
- The mother is less than 145 centimetres tall.

Warning signs during pregnancy include the following.

- The mother does not gain weight (she should gain at least six kilograms during her pregnancy).
- The mother's skin inside her eyelids is pale (it should be red or pink).
- The mother has unusual swelling of the legs, arms or face (though some leg swelling is usual in later term).

Four emergency signs

You should get help immediately if the mother:

- starts to bleed from the vagina;
- has severe headaches (this could be a sign of high blood pressure);
- starts to vomit (be sick) severely, especially after the second month of pregnancy; or
- has a high fever (temperature).

Delivery

At about the eighth month of pregnancy, the unborn baby begins to move into a head-down position, gather fat and develop reflexes at a rapid pace, all to prepare for birth and early survival.

When the baby is ready to be born (at about the 40th week of pregnancy) a hormone *oxytocin* causes the muscles to contract and the mother goes into labour. With a first child this can last 17 hours or more. Newborn babies often look red and battered, with misshapen heads, but these effects don't last long. More dangerous is a lack of oxygen. This is sometimes caused by the umbilical cord being wrapped around the baby, or the baby holding and squeezing the cord. Brain damage can occur if the brain cells cannot receive oxygen for several minutes. Having help at the birth or having the baby in a hospital or clinic can lower these risks.

Babies born early (pre-term or premature babies)

How the early baby develops depends directly on the quality of the care they receive and the environment they are born into.

Many babies are born before 37 weeks (or 259 days) of pregnancy. This can be because:

- the mother is very young and her body isn't fully developed for pregnancy;
- the mother is having a multiple birth (twins or triplets); or
- the mother's condition or health is poor or she is under unusual stress.

Babies born very early often have little fat to protect them and their lungs can't take in oxygen easily. They may not have developed the reflexes which they need to suck or swallow.

Chapter 6:

Important stages in your child's development

The 'normal' (average) development of children follows certain patterns. If you care about your baby's well-being and the advances they are making, your baby has a greater chance of developing all his or her potential.

Newborn babies and the first months of life

Month one: Babies are active from birth, and their reactions are the best signs of healthy development. During the first few days it is important that you remember the following:

- You must handle your baby gently and make the change from their life in the womb to their new life as smooth as possible.
- A newborn baby's head needs support to stop it flopping backwards.
- A baby's needs are simple: they need to sleep for long periods and get food and water from their mother's milk. Breast milk is the best food to help babies to grow and develop.
- A baby should be breastfed regularly (often every hour or two) during the first few days so they get the colostrum which contains antibodies to protect them. It also helps the mother and baby to practice nursing while the breasts are still soft. Even at night your new baby should be fed at least every four hours. Sometimes young mothers need help to learn how to breastfeed.
- Begin the immunizations for babies that your health worker recommends.

Normal development

During your baby's first month watch for them:

- making jerky, quivering arm thrusts;
- lifting their hands up to their eyes and mouth;
- moving their head from side to side while lying on their stomach;
- keeping their hands in tight fists;
- making strong movements with their legs and arms, and pulling faces.

However, you should remember the following:

- Babies are different – some don't like cuddling, while others do.
- Some babies get very upset by activity or change in their surroundings, while others don't and sleep much of the time. Both are normal.

Health watch

You should get the help of a doctor or health worker urgently if your baby:

- does not seem well and has diarrhea or fever;
- sucks poorly and feeds slowly;
- does not blink when shown a bright light;
- does not focus to follow a moving object;
- has very loose or floppy limbs;
- has a trembling lower jaw, even when not crying or excited; or
- does not respond to loud noises.

Warmth is very important for premature and small babies. When a baby is very cold their behaviour changes – they no longer cry or move. You should move the child to a warm room and wrap them in a blanket.

The first six months

A baby gains weight rapidly during this time. They:

- begin to smile around six weeks;
- discover their hands;
- focus on objects and people's faces;
- develop full colour vision and find objects that are partly hidden;
- explore with their hands and mouth;
- struggle to get objects that are out of reach; and
- respond to their own name and begin to understand "no" as they learn to recognise different tones of voice.

During this time they also begin to make sounds when they hear sounds, and they can show that they are happy. They also start to develop language by babbling chains of sounds (for example, bababababa, or mememememe).

Play is important to help developing babies use all their senses. Play is anything that stimulates their bodies and their senses and develops their thinking and intelligence.

Holding a baby to the shoulder is the most effective way to stop them crying. Different cultures have different ways of handling or carrying babies when they cry, but research has shown that holding a baby to your shoulder works best. Other effective ways include rocking and swaddling. Swaddling a baby involves wrapping them tightly in a blanket so they cannot move their arms and legs. This stops them from moving and reduces the jerking in their arms and legs, helping them to become calm. Sucking is another way babies calm themselves; sometimes feeding provides more than food, it can also provide comfort, even when there is no milk. You can also give your baby other safe objects to suck on. Remember that breastfeeding is essential for babies until they are at least six months old, wherever possible.

Normal development

By six months, your baby should be able to:

- raise their head and chest when lying on their stomach;
- stretch their legs out and kick when lying on their stomach or back;
- open and shut their hands;
- push down on their legs when their feet are on a firm surface;
- bring their hands to their mouth;
- take swipes at dangling objects;
- roll both ways – from on their back to on their stomach and from their stomach to their back;
- sit with some support;
- support their whole weight on their legs;
- reach out with one hand; and
- transfer objects from one hand to the other.

Health watch

You should get the help of a doctor or health worker if your baby:

- has difficulty putting things in their mouth;
- does not roll over by five months;
- does not smile (unless you touch them) by five months;
- cannot sit at all by six months;
- does not make any sounds by six months;
- cannot bear weight on their legs or reach for objects by the end of six months; or
- does not babble by eight months.

You should also get help if one or both of your baby's eyes turn inwards or outwards.

Six months to one year

Your baby's growth slows down during this time, but it is regular. Growth sometimes slows down or stops because of illness when your baby might not put on weight for several weeks. When your baby reaches six months, most of the nutritious foods that families normally eat are good and appropriate for them. You should introduce them gradually, and one by one. By this time your baby will have begun teething – first with the bottom front teeth (incisors) and then the upper front teeth.

You should pay special attention to speech: if you listen and reply to your baby's early language, you will provide the stimulation that babies need most. Your baby's ability to speak comes slowly but their ability to understand words comes rapidly.

You must protect your baby from actions that are not safe, even if this makes them angry and frustrated. Apart from pain, illness or hunger, crying is either a signal for you to act to put things right, or it is an explosion of frustration and anger. You can learn to understand what is causing most of the crying and find helpful ways to deal with it.

Normal development

Watch for these signs within your baby's first year:

- Your baby begins to control their muscles from the top down (head and arms before hips, legs and feet).
- By eight months your baby will be able to sit without support, at least for a short time.
- Some children never crawl but go straight to walking.
- Standing and walking happen together, and most babies pull themselves up by end of the first year.
- By 10 months your baby will have developed the 'pincher grasp' – using the first finger and thumb to pick up tiny objects.
- Your baby will be focusing on small objects and they will be able to hold different shapes.
- Your baby can put objects into a container and take them out.
- Your baby will be able to drop objects deliberately.
- Your baby will be poking with their index finger.
- Your baby will try to scribble on paper with pencil.
- Babies understand language long before they can speak. They should say the first real words or sounds they invent by the time they are 11 or 12 months old.

Health watch

You should get the help of a doctor or health worker if by 12 months your baby:

- has been dragging one side of their body when crawling for more than a month;
- cannot stand when supported;
- does not search for objects which you hide while they watch;
- does not say single words (like 'mama' or 'dada');
- does not use gestures such as waving or shaking their head; or
- does not point to objects, people or pictures.

From one year to three years

Children's behaviour becomes much more complex between the ages of one and three. They:

- begin thinking and reasoning about people and objects;
- begin to imitate, communicate and 'pretend play'; and
- have new types of social relationships between themselves and their caregivers.

Toddlers this age will be teething through most of the second year which may make them irritable and cause pain, though each tooth takes just a few days to come through. It is very important that your child begins to think and reason. As they respond to sights, sounds, feelings, smells and tastes, their brain develops more rapidly. Hand skills also develop rapidly – there is no need to force your child to use their right hand; their brain decides whether they are right-handed or left-handed.

The age of two is an important stage for development. This is the age when the child moves from being the 'centre of the world' to a 'social being' (in other words, they realise that there are other people in the world and they are part of a larger community). This usually doesn't happen without several major changes taking place.

It is common for a child to be antisocial or refuse to cooperate with other children. They are often upset about having to share toys. A child this age likes to copy what older children do and you should give them a chance to be helpful as this is an important social skill.

Some two-year-olds are aggressive, even biting and hitting. You should lay down firm limits and stick to them, as well as giving your child plenty of chances for exercise. *You should not encourage aggressive behaviour* (sometimes this is encouraged in boys), nor should you hit your children to punish them. This only teaches them that hitting is allowed.

You can help small children to play and think for themselves. You can help them to carry out tasks through games and suggestions (though not doing the whole task yourself). You can also encourage children sit still for a few moments as well as encouraging them to play with other children.

Normal development

Watch for these signs during these years

- By one year old a child can roll a ball, while by 2 ½ years, they can throw it.
- By 15 months they can hold a cup of milk, juice or water.
- By 15 months they can eat rice or thick 'papa' with a spoon.
- By two they can name objects in a simple picture book.
- By two years old a child can dress themselves with simple clothes (but not buttons, zippers, laces and so on).
- Speech develops more after two. A child will use short sentences, repeat conversations and take simple instructions.
- Children can turn the pages of a book, build a tower with up to six blocks, make shapes from clay and, by the age of three, string beads.

Health watch

Get the help of a doctor or health worker if a child:

- cannot sleep or eat or seems to be in constant pain other than teething, for example putting their hand on the side of their face (earache);
- cannot clap their hands or stand up;
- does not walk heel-toe after several months, or only walks on their toes;
- does not speak at least 15 words by 18 months old;
- does not use two-word sentences by age two;
- does not imitate actions or words; or
- does not follow simple instructions or cannot push a wheeled toy by age two.

6. Important stages in your child's development

From three years to six years

Change becomes slower from three to six years. Children lose baby fat, their legs grow longer and thinner and they start to move around with more skill. Children can talk a lot at this age, but also like to listen to stories.

Although they are becoming independent children still need help in learning to tie a knot, hold a pencil and so on. They can eat by themselves, but they seem to eat less food than before, which is normal.

A child's mental and physical development is affected by their environment. The body, brain and nervous system need a healthy environment for normal growth. Nutrition is also important, as is the opportunity to play and be active. Although everything a child does helps their development, each one develops differently. The child develops language skills rapidly at this age, including a second language when caregivers speak different languages. You should speak clearly and pause for children to understand, though you don't need to use baby talk. Games like rhymes that repeat words help children's brains develop through language.

You can help by giving your child a chance to say the right words and ask correctly for objects. You can also use objects to illustrate what is being said, practice questioning with your child and encourage their curiosity.

Normal development

Watch for these signs during these years

- Children this age develop a wide range of emotions, from happiness to sadness, anger and excitement.
- Children change how they play over weeks and add new ideas to familiar games.
- Curiosity is important; you shouldn't teach children to be afraid of people, animals (with your guidance), climbing (with your guidance) and so on.
- Children can start and enjoy a relationship with other children.
- A child should sometimes resist authority, though you should not allow your child to constantly refuse to follow instructions.
- A child should remain interested in things other than themselves and be able to carry out simple tasks.
- A child can show affection for one or more people at this age.
- Although children have fears and anxieties at this age, they should also be able to take part in and enjoy life, which shows they will outgrow their fears.

Health watch

Get the help of a doctor or health worker if a child:

- is still very fearful or timid by six years of age;
- cannot leave you without getting very upset;
- cannot concentrate on an activity for more than five minutes;
- cannot hold a pencil;
- shows little interest in playing with other children or seems unusually passive;
- rarely uses fantasy or imitation in play;
- seems unhappy or sad much of the time;
- does not show a wide range of emotions;
- often has trouble eating, sleeping or using the toilet;
- cannot understand two-part commands;
- cannot correctly give their first and last name; or
- does not talk about their daily activities and experiences.

Chapter 7:

Understanding and including children with disabilities

Victor Pineda said:
“Every person in the world looks different and has different ideas, experiences, traditions and abilities. I learned that these differences create new possibilities, new hopes, new dreams and new friendships.”
(From *It’s About Abilities! 2006, UNICEF and Victor Pineda Foundation*).

Children are all different. They come in different shapes and sizes, and with different talents and abilities. They each have skills and capabilities to share with their families and communities. They also have a lot to teach us if only we give them a chance. This chapter outlines ways that parents and teachers can understand and include a variety of children with a variety of disabilities.

All children are perfect just the way they are. Children may have difficulty hearing, seeing or getting around and it is our responsibility to make sure they have the tools they need to succeed. Sometimes it is easy to see that a child has a disability so their needs can be easily understood. Sometimes a child may have a disability that is not easy to see and their needs may be difficult to understand. No matter what challenges a child may face, schools must be willing to accept them, include them, and provide them with the tools they need to succeed. This includes helping them to obtain “assistive technologies” such as equipment that is adapted to meet their needs.

This chapter provides a list of common impairments or difficulties that can be the result of different diseases. It is useful to think about the difficulties a child may have because the solutions which help one child can often help other children and learners.

Visible and invisible disabilities

In this chapter we will talk about visible and invisible disabilities. We don't necessarily mean whether you can see them or not. We accept some disabilities because they are obvious or have an outward sign. For example, you can't see deafness but because some deaf or hearing impaired people wear hearing aids or use sign language, we know that they have a hearing impairment. The same thing applies to people who are blind or vision impaired. They may wear glasses, carry a cane or have a guide dog. We recognise that these people have a disability. But what about all those people who have a hidden disability that is just as devastating as the ones that we can see? Because we cannot see their disability, is it more difficult to understand? Can we help them as we would help someone with a wheelchair?

Disabilities which affect learning and remembering

These can be the result of conditions such as:

- **dyslexia;**
- **dyscalculia;**
- **developmental co-ordination disorder (DCD);** and
- **attention deficit disorder and attention deficit hyperactivity disorder (ADD/ADHD).**

While a child's school programme should be as closely in line with the general education curriculum as possible, some changes and modifications may be necessary. Listed below are some ways that parents and teachers can help children with specific learning disabilities to learn more effectively at home or at school. The methods chosen must be based on the individual needs of each child.

The child, their parents, and their teachers must all be involved in developing the child's education programme so it meets their individual needs. Children with more than one learning disability need programmes which meet all their different needs.

7. Understanding and including children with disabilities

Impairments: common causes and solutions

Impairment	Common causes of impairment	Solutions and helpful aids
Mobility	<p>Muscular dystrophy Spinal cord injury, paraplegia Cerebral palsy Amputation Spina bifida Polio Traumatic brain injury (TBI) Juvenile arthritis Club foot</p>	<p>Manual and motorized wheelchairs Strollers Canes Braces, aids to help posture Crutches Walkers and walkers with wheels</p>
Visual	<p>Cataracts Osteoage Albinism Aniridia Traumatic brain injury (TBI) Coloboma Cortical visual impairment (Cvi) Glaucoma Optic nerve atrophy Optic nerve hypoplasia (Onh) Retinopathy of prematurity (Rop) Nystagmus</p>	<p>Different glasses Braille books, Braille keyboards Magnifying lenses Assistive Technology Cell (mobile) phones Access to websites Personal digital assistance Optical character recognition Text-to-speech software Screen readers Electronic books</p>
Hearing and speech	<p>Otitis media (conductive hearing loss) resulting from the following.</p> <ul style="list-style-type: none"> • Ear infections • Mumps • Measles • Chickenpox • Brain tumors • Damage to the inner ear 	<p>Sign language, hearing aids Hearing aids Audio amplifiers Vibrating alarm clocks Safety visual alarms, alarms with lights Teletype and pagers, text-based phones Relay services and web cams Television captions SMS and instant messaging</p>
Speech	<p>Stuttering Aphasia Dysarthria Dysphonia Neurological causes such as strokes, head injuries, brain tumours, autism</p>	<p>Speech communicator Visual communicator Communication software Speech therapy Artificial larynx (voice box)</p>

Ways to help children with specific learning disabilities

Reading For children who read slowly or who find reading difficult, a 'read-along' technique can help. Children learn by listening to tapes of texts while following them in print.

For children who read below expected levels, videos and films or talking books can give them the general information they cannot get from printed material.

Children who have difficulty reading handwritten, small or crowded print can use typed handouts in large print. Double-spaced materials can also help.

Memory Children with memory problems or difficulty taking notes may share another child's notes, or they could tape lessons or ask the teacher for a copy of lesson outlines.

Children with short-term memory problems might be able to understand mathematical processes, but their problems can interfere with remembering mathematical facts. These children will find a table of facts or a calculator very useful.

Listening Poetry, rhymes, songs and audio-taped materials can develop memory and listening skills.

Spelling Children who have difficulty with spelling can use a 'misspeller's dictionary' or computerized spell checker. Spelling should be taught using a number of skills including speaking, spelling aloud and writing the words.

Vocabulary A child's vocabulary and comprehension can be improved by creating a personal file of words they need to learn to use. 'Word webs' which link words and ideas together, and other ways to relate on paper words and ideas heard or read can also help. A dictionary or thesaurus, suited to the child's level of learning, is an excellent tool for helping with vocabulary, spelling and reading.

7. Understanding and including children with disabilities

Organising Children who have difficulty organising their time, materials and information can be helped by a range of approaches including:

- a quiet, tidy homework space;
- an alarm watch;
- texts that they can mark with a highlighter;
- a homework assignment diary to use both at home and at school;
- instruction in how to develop study skills; and
- a personal diary for scheduling their work.

Writing Children who write slowly or whose handwriting is illegible or includes many reversed letters could use a cassette recorder or a computer with word processing software for written work or tests.

Children who can't copy accurately but who need practice in writing can be helped by teachers who:

- leave a space directly under each word, phrase or sentence;
- provide handouts for those who can't copy from the blackboard or take dictation accurately;
- provide a list of words in the right margin for left-handed children; or
- provide enlarged spaces for 'fill in the blank' activities for children with large writing.

Speaking Children who need time to take in spoken information need patience. They may not fully understand questions they are asked, have problems recalling information, or struggle to form an appropriate answer. Teachers should give these children enough time to answer or provide the questions in a written form.

Oral and written language should be taught together as much as possible. Illustrations in a book should be used to encourage conversation about what is being read. Material that is read can be turned into a spoken summary, a word web which links the ideas together or a computer presentation.

7. Understanding and including children with disabilities

Photo: J. Schenk



We know that children are all different – and all children are special. But some children are special in ways that present them and their families, friends, and teachers with more difficult challenges. However, children with disabilities offer a wealth of experience to their classmates in skills such as listening, sharing and being patient with others.

Chapter 8:

Child safety and protection

Children with disabilities need to be kept safe like all children. Families need to know about the differences between real and imagined risks and how to reduce them.

However, some children with disabilities complain that their parents don't let them get about, or move enough. Many parents are over-protective of children and especially of children with disabilities. They have been told by friends or professionals that it is best not to touch or hold a baby with certain conditions, or that a young child with disabilities doesn't need exercise. Quite the opposite is true. Like all children, those with disabilities need attention, yet sometimes they need a different sort of attention than their brothers, sisters or friends of the same age. They do need stimulation and it is very important to work with an occupational therapist who can show you the best ways to help your child get the movement and exercise they need.

Safety in the home

If parts of your home are dangerous for a crawling baby or children playing, take care to put up barriers. Dangerous areas include stoves and fireplaces, balconies without railings and stairs (even low stairs). In some countries it is an offence not to put barriers on balconies, stairs or windows where children could fall. Many countries regard this as a serious form of neglect.

Make sure that the floors are safe for children who are moving about. Electric cords, curtains and other articles like lamps can be dangerous and you should keep these away from the children's beds as well. Children with wheeled aids, including wheelchairs, need a safe ramp to enter and leave the house. Other aids can help children get around safely way, or help them sit, stand or lie in correct positions. You must carefully examine all equipment to make sure there are no sharp edges or pieces that will break.



Other things to watch out for

Equipment should be adapted to the child's needs, fitted by professionals, and updated as the child develops.

Toys for children with disabilities are increasingly available for sale, and you may also make toys for your child. You should take special care that toys can't break and injure the child, or be swallowed. You should also avoid paints unless they are 'child-proof' and not dangerous if your child puts the toy in his or her mouth.

Don't leave a child alone on a sofa or bed where they could fall off or be smothered by pillows. Don't leave plastic bags on the bed with a baby and don't put beads and necklaces on small babies. Other dangers to your child's health and safety include the following.

Burning: When you are holding a child in your arms, do not cook at the stove, lift boiling water or carry out any other

Dangerous areas include stoves and fireplaces, balconies without railings and stairs. Good examples of safety in the home can be created by parents, like this barrier around a stove.

8. Child safety and protection

dangerous activities. Check your child's bath water is not too hot. Test the temperature with your own hand for 10 seconds.

Smoking: Do not smoke near your children – they will inhale more dangerous substances than you when you are smoking.

Words of advice

“Secondary disabilities” are complications that can appear after, and because of, the original disability. You as parents can help prevent these. For example a child with polio or cerebral palsy who at first is unable to walk gradually loses the normal range-of-motion of joints in her legs. Shortened muscles, called ‘contractures’ keep her legs from straightening. This secondary disability may limit the child’s ability to function or to walk even more than the original paralysis.

Most contractures can be corrected but it may take a long time: *Prevent contractures before they start!*

Other secondary disabilities can result from medicines for fits, from crutches, ill-adapted braces or from surgery. Always seek the opinion of therapists and other professionals before deciding to have an operation. Have your child’s needs evaluated carefully and repeat the evaluations regularly over time.

Paraphrased from Disabled Village Children, 2006 edition

Protecting your child from abuse

You are responsible for your child’s safety and well-being. As well as taking measures for your child’s safety, protecting disabled children from abuse is especially important. There are four main types of child abuse:

Telling a child she or he will never be able to perform certain tasks or to learn is a form of abuse.

Emotional abuse. Your child has the right to respect and dignity. Emotional abuse includes name-calling or saying negative things about your child. Do not criticise what your child can do (even if you think they don’t understand what you are saying) during doctor’s or friends’ visits. Telling a child she or he will never be able

8. Child safety and protection

to perform certain tasks or to learn is a form of abuse. In families where several generations live together, it is important that all generations understand how to protect a child emotionally and that no one abuses the child or the child's parents through speech or actions.

Families must work together to give their child with disabilities all the emotional support he or she needs.

In school or at play, emotional abuse is still too common: mocking, jeering and bullying must be tackled immediately by teachers, parents and children.

Mocking, jeering and bullying must be tackled immediately by teachers, parents and children.

Photo: M.E. Chatwin



Words of advice

Children who have language or speech disabilities will need other ways to express themselves so they can be protected while taking part in social activities. You should teach your child to say or write their name, address or phone number, village or family name in case there is an emergency or they get lost.

8. Child safety and protection

Be sure you know who is taking care of your child and their attitudes towards your child's behaviour. Be clear with them that you do not tolerate physical abuse or punishment.

Physical abuse includes aggressive behaviour and cruelty such as hitting, pinching, pulling or pushing the child to make them afraid, or not allowing a child to move by tying or caging them. For a child to feel safe and develop, they need protection from strangers, classmates, teachers or family members who might abuse them. You should not punish your child physically, such as by hitting them. 'Positive parenting' rewards good behaviour and is much more effective than physical punishment. For example, not allowing a child to play with a favorite toy for one day can show him or her that hitting or throwing things is not allowed.

Be sure you know who is taking care of your child and their attitudes towards your child's behaviour. Be clear with them that you do not tolerate physical abuse or punishment.

Words of advice

It can be difficult to know how children with attention deficit syndromes will behave. They may take risks by climbing high in trees, standing on a stove, or demonstrating anger in unusual ways. As a result of these impulsive feelings, they may have accidents, or their behaviour might make others angry, or they might even accidentally hurt others. Sadly, these children have been seen tied to their beds or to a tree, or even put in a cage. Inhumane treatment like this must not be tolerated and is against a child's human rights. These children need strict limits and firm but kind guidance from parents. They also need to learn that their unsafe or antisocial behavior can have serious results. They can be taught other ways to express frustration.

Disabled children often think that no one will believe them, but you must always listen to them carefully.

Sexual abuse. Children with disabilities are more likely to be sexually abused than children without disabilities. This happens most often within the child's family or from close friends or neighbours. If you have to leave your child, you must consider carefully who will be looking after them. If your child's behavior changes or if they seem afraid, you should take it seriously and take steps to protect them, changing their carer if necessary.

Children with disabilities may not be able to resist or avoid abuse. Sometimes a child with disabilities needs more help with 'intimate personal care' such as visiting the toilet, and this can lead to sexual abuse. The child may have difficulty telling you what is happening to them, and they may be afraid to tell because they might lose the services of someone who is helping them, but also abusing them.

Children's institutions or orphanages have very high rates of sexual and physical abuse, but also neglect and emotional abuse.

Disabled children often think that no one will believe them, but you must always listen to them carefully. Being alone and having no support is a dangerous factor for sexual abuse; be sure you as parents have outside contacts and support. A child and his or her parents must know who they can turn to if they suspect abuse. A qualified social worker, a health worker or support group could provide help. You should also consider contacting a local community organization, a school or someone with links to national services or international organizations.

Neglect is often linked to physical abuse, since the results of neglect are sometimes dangerous for life and health. Neglect to children with disabilities might include ignoring their safety needs, but also includes leaving them for long periods without any care, without changing their bedclothes or diapers (nappies) or giving them food. Parents who work cannot leave their child alone for hours while they are away, without sufficient care.

Parents who work cannot leave their child alone for hours while they are away, without sufficient care.

Children with disabilities who have been neglected often develop bed (pressure) sores that can become infected. Parents who need to leave home, for example for work or to take other children to school, must take extra care that their caregiver is appropriate and does not abuse their disabled child. You shouldn't leave your disabled child in the care of other children.

Chapter 9:

Helping your child to be included and respected

In this handbook we have looked at many aspects of what it is like for a child to live with a disability, and how you as parents can understand, work with and care for your child. At the same time, you as a parent will be the child's advocate – the person who defends their rights and well-being. In this chapter we look again at some of this handbook's most important messages to you, the parents.

Negative language about impairments and disabilities strongly affects children.

Remember that using negative language about impairments and disabilities strongly affects children. It is important to think about the language we commonly use to describe people, and check the meanings of our words and the ideas associated with them. Parents, brothers and sisters, and others in the community – especially teachers – must ask speakers not to label people with impairments, often with hurtful phrases or words.

Negative language about impairments and disabilities strongly affects children.

Remember that a disability is the result of the barriers placed by society on people with impairments. People with impairments often can't play a full part in society because of the attitude of others, or because of problems with their surroundings. An example of a disability would be a child with cerebral palsy who wants to sing with others but is left out because people think they would not be able to sing in tune with the group. We must try to treat 'disability' as a problem with society, and 'impairment' as a medical or individual issue. This helps us to clearly see the two issues a person may be facing and also helps us to take the necessary actions to find solutions.

9. Helping your child to be included and respected

We hope that you also will take a 'rights-based' approach to disabilities. This approach is based on the United Nations Convention on the Rights of the Child (CRC) and the United Nations Convention on the Rights of Persons with Disabilities which state that children and adults with disabilities have the same rights as everyone else. These conventions try to make sure that people with disabilities are included in any action, laws, programmes or policies that are developed that affect them.

Parenthood is also about developing and adapting. As parents you will learn new skills from caring for your children. The family can do much to influence how its children develop and the most important influence on the development of babies and young children is the quality of the care they receive. Parents, families and caregivers are the most important people to raise children, pass on their culture and make changes in society that will help their children.

Remember that discrimination takes many forms. It can affect many people including girls, disabled children and ethnic groups. If a child is disabled, the community must take extra care to make sure they are not stigmatised or made the victim of discrimination. People with disabilities may face disapproval all their lives in their communities, and even in their own families.

A community that does not work with or support people with disabilities will never challenge its own attitudes. Children with disabilities are too often placed in institutions or orphanages. In some countries parents are led to believe that their children will have a better life if they are put in special institutions. The best place to grow and develop is in a family atmosphere, even if this means living in a home with a small group of other people or living in a small institution with personal care.

Every woman should have a healthy pregnancy and a mother can take steps to give her baby the best chances to grow and develop as well as possible. If a mother receives proper medical care while she is pregnant, the developing baby has a lower risk of impairment. Women

Children and adults with disabilities have the same rights as everyone else.

The most important influence on the development of children is the quality of the care they receive.

If a child is disabled, the community must take extra care to make sure they are not made the victim of discrimination.

The best place to grow and develop is in a family atmosphere.

If a mother receives proper medical care while she is pregnant, the developing baby has a lower risk of impairment.

9. Helping your child to be included and respected

in some cultures have so many responsibilities that they barely have time for their children. Because pregnant women should avoid heavy chores, men and boys should take over some of them, such as growing and marketing food and washing clothes, during this important time. This will greatly help protect the health and development of the unborn child.



Photo: A. Montanari

Make regular visits to a health worker to check your child's needs.

As your child grows and develops you can help them to develop all their abilities. After birth, immunizations are important, and you should make regular visits to a health worker to check your child's needs. Family members can work with occupational therapists and learn to help a disabled child exercise or move about, or learn skills.

When possible, disabled children should go to school.

When possible, disabled children should go to school. After reading the other chapters of this handbook, we hope that you, as parents, are more confident that your disabled child can and should go to school to be educated. We hope you have discovered that all children want to develop their possibilities. We discussed how you should not always keep your child at home, indoors, or away from school because of shame or because you are overprotective.

9. Helping your child to be included and respected

There is a great need for you to insist that your child is included. A very simple approach is best, raising the awareness of teachers and school officials about all children's right to be included. Persuade other parents to insist that training for teachers is necessary. You can ask the international organizations involved in education to help. You should work out practical ideas for getting your child to school before you contact local or larger organizations. Sometimes roads are difficult, or there are no roads at all, so children who cannot walk are disadvantaged.

If school is not possible, the family and community can find ways for disabled children to learn at home. They can fill a number of roles in the community. For example, if they cannot walk but like to read and write, they can become a librarian and start a community library or work in a local office. Communities should always consider choosing people with disabilities to fill roles. If a child cannot see, they often can learn to play a musical instrument, learn Braille script and contribute actively to community life.

Insist that your child is included.

Communities should always consider choosing people with disabilities to fill roles.



9. Helping your child to be included and respected

Activities such as farm work and gardening are important in many villages. Children can learn to care for animals and to garden. Even children who are blind can get about outside if parents make sure they are safe, by building handrails to guide the child, for example. A child in a wheelchair can work in the garden if the ground is raised to a higher level. Parents and families often have very imaginative ways to help their child take part in all activities, inside and outside of the home, in school and at work: a child who is mentally impaired but physically strong might learn physical skills such as milking the cows and help in daily chores. A child who is physically disabled but has a quick and intelligent mind might prefer to learn mental or computer skills rather than try to carry out physical tasks that are difficult for her.

It is important for children to learn how to look after themselves and to develop daily living skills.

However, in all cases, it is important for children to learn how to look after themselves and to develop daily living skills such as preparing food, keeping house, communicating with others and so on, even if they find it difficult.

Consider respite care.

You as parents, and family members, will be giving children most of the care they need. Sometimes you have a lot to do and there may not be enough time to spend with your disabled child for important activities such as play and learning. If this is the case, you might consider respite care. This offers occasional chances for your child to stay with others you trust, for a few hours at a time. 'Respite' is similar to 'rest' and gives parents and families the chance to let others help with their child. Sometimes you can organise respite care with a neighbour in exchange for other services.

Parents and other community members such as teachers can form a group and set up a centre in a community building or someone's home. They can use the centre as a meeting place to discuss how to include their children in more activities and also to take turns caring for other people's children once a week or more. Toys and books can be collected and kept for the children who come to the centre, and caregivers will learn each child's needs. This also gives children the chance to meet other children or other carers.

9. Helping your child to be included and respected

Photo: J. Schenk



Please share this book with other parents and parents-to-be, with community members such as local officials and with school staff like teachers and school directors. We hope that our support and the information we give you will benefit your family and help children to be included so that they too can contribute to their families and communities.

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World Vision is a Christian relief, development and advocacy organisation dedicated to working with children, their families and communities to overcome poverty and injustice.

**Including All Children!
Guidelines for parents of children with disabilities**

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Today we have the means and the duty to raise awareness about children with disabilities. It is often their parents and families who need support, and this book is dedicated to those who care and encourage all their children – regardless of their abilities – to participate in family and society.

This is not easy. Many cultures have not questioned old traditions of stigma against people with disabilities. We hope today's parents can begin to turn this around.

The purpose of this book is to inform and encourage parents of children with disabilities so that all children's rights are respected.

This book looks at:

- Why positive language can encourage a child to succeed beyond the limits created by their physical condition.
- Why society “creates” disabilities for people who have limits of different kinds.
- How parents sometimes think there is “no point” in helping their child with disabilities to develop.
- Why the most important influence on the development of babies and young children is the quality of the care they receive.
- What rights children with disabilities have.
- How parents can keep children safe and protected – while giving them the freedom and encouragement to develop.