



The Kyrgyz disability guide

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What is this Guide about?

Welcome to The Kyrgyz Disability Guide. This guide has been developed for parents of disabled children, disabled people and others who work with disabled people. Primarily, it provides information, support and advice for disabled people and parents of disabled children, although it also will be useful for organisations working with disabled people and other members of the community who should be or want to be informed about disability.

This Guide has been designed so that it is practical and easy to use. It provides:

Part 1 Views and visions, information, questions and advice

Part 2 Communication and development

Part 3 Rights

Part 4 How does the system work, which professional is involved

If you look at the next page 'Contents' you can see which information is interesting for you and which part of the guide is not. It is not necessary to read everything, just chose the topics that interest you.

This guide does not have all of the answers because unfortunately there are often no set answers about what should be done to support children with disabilities. Every child is an individual and needs an individual response, although there are lots of general principles in this guide that can be applied to many children.

The systems in Kyrgyzstan can be unclear and can operate differently from area to area and even organisation to organisation. Consequently you may find additional services or fewer services in your area than are talked about in this guide. What I have tried to do is to give you as clear a picture as is possible and a variety of different options about what you can do to get the best for yourself, your children and your family.

As parents or disabled people you may not always agree with the approach and philosophy I promote in this guide. The advice and examples I may give you may feel irrelevant or inappropriate for you and your family. It is impossible to meet the needs of all families in one guide as everyone has a different approach to dealing with the challenges presented by disability. I hope that you use what is useful and develop your own strategies when you feel that my suggestions are inappropriate or unhelpful.

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*Part 1 Views and visions,
information
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Definitions of Disability

In different countries and even in different communities people have a different idea about what disability is. In this manual I use this definition of disability:

The disadvantage and exclusion which arise as an outcome of the interactions between people who have impairments and the social environmental barriers they face due to the failure of society to take account of their rights and needs.

There is a very important distinction in this definition between impairment and disability.

An impairment is **a physical, mental or sensory characteristic or condition, which places limitations on an individual's personal or social functioning in comparison with someone who does not have that characteristic or condition.**

In other words, **impairment is individual.** There are as many different impairments as there are impaired individuals. An impairment can be the result of illness, injury, or a congenital condition. For example, different impairments can affect someone's physical mobility or dexterity, his ability to learn, to communicate or interact with other people or to hear or see.

In contrast, **disability is social.** It is the exclusion of people with impairments, due to social and environmental discrimination that acts as a barrier to their full and equal participation in mainstream society. Disability is fundamentally an issue of rights.

In day-to-day speech, the words impairment and disability are often used interchangeably. It's easy to think that they are the same and that disabled people's participation in mainstream society is limited purely because they have an impairment.

However, having an impairment does not necessarily limit or exclude people. For example, in marathons wheelchair users compete separately from runners, because they are so much faster over a long distance on level ground. Yet the same wheelchair user who beat all the runners might not be able to attend a social event after the marathon, if it is held in a building with steps. This is not because he uses a wheelchair but because the building was not built in an accessible way. This is not because of cost – building a ramp would have cost the same amount as building steps – but because the architect and builder did not consider disabled people's access.

In other words, the wheelchair user is excluded because her needs are not considered as important as those of other people – she is excluded as a result of (often unconscious) **discrimination.**

Discrimination limits disabled people's most fundamental rights. Where polling cards are not available in Braille or another accessible format, blind people are denied their right to vote. Where schools have no sign language translation, Deaf people are denied their right to education. Where hospitals do not provide information in simple, accessible ways, people with learning difficulties are denied their right to know what is wrong with them or to make decisions about their treatment. Where wells or latrines are physically inaccessible, people with mobility impairments are denied their rights to clean water and sanitation.

Every Child understands disability as the **exclusion** of people with impairments from family and social life, equal education, employment and access to basic services because of discrimination.

This is also known as the **social model** of disability. Every Child uses the social model because it has been developed by disabled people, and best represents their experiences and perspectives.

The social model of disability is often contrasted with the **medical model**, which says that disability is the same as impairment, and so disability can be fixed using medical treatment or therapy alone.

Whilst Every Child is committed to supporting appropriate clinical and therapy services for people with impairments, we believe that this is not enough on its own. It is essential to address the specific needs people have as a result of their impairment. For example, a Deaf person needs to learn to sign, and a polio survivor may need crutches. However, a Deaf child who can use sign language still cannot communicate if her parents, teacher and classmates don't learn it too. A woman who has crutches is still unable to get a loan from a microcredit programme if there is a policy that loans will only be made to women in good health. It is also essential to address these discriminatory barriers.

Although a good definition is important, the most important is that you understand that the problems that disabled people face on a daily basis, are not caused by them, but by the society/community who does not accept their impairment and disables them. It is therefore that the solution for the problems of disabled people lay in the society/community.

We can only overcome disability by addressing the social barriers that discriminate against and exclude people with impairments. It isn't enough for the impaired individual to change – people without impairments must change too.

Approach and Philosophy to Disability

An estimated 10 percent of the world's population have a disability. Most of these people live in developing countries. Disabled persons are among the poorest of the poor in the world and therefore live under very vulnerable conditions. Poverty does not only mean lacking food, housing and an income, it also means having no influence on political, social and economic conditions. Lack of access to education and information are also consequences of poverty.

The discrimination which disabled people encounter has several causes. Negative attitudes and misconceptions about disability are one of them. Lack of political determination to harness the potential of disabled people is another. Discrimination excludes disabled people from social development, which very often means social exclusion as well.

For many years now the international disabled movement has been working to promote respect for the human rights of persons with disabilities. In recent years this question has also been discussed within the UN Commission for Human Rights. But human rights are still relatively uncharted territory where people with disabilities are concerned.

However, is now commonly advocated by many countries that our approach to disability should concentrate on including disabled children from a human rights and equality perspective rather than a focus on the child as faulty. If we only see the child's impairment as the "problem" then the only solution is to develop medical services that try to cure the child's impairment. Research shows that the majority of impairments, although may be improved, cannot be cured. Although many parents put their hopes and belief's into the dream that their child can become normal, often the reality is that children will always have their disability.

Alternatively we can look at the problem as being the fact that society does not accept disabled people and excludes them. Society dictates that disabled people cannot:

- Study in mainstream schools (It fails to develop appropriate curriculum's, train teachers, or make buildings accessible to meet the needs of disabled people)
- Work (It fails to find jobs for disabled people, stop discrimination against disabled people and support disabled people in the workplace.)
- Be included in society (It fails to promote a positive image of disabled people, make community buildings and resources accessible.)

In order to understand how the approach to disability can impact on the lives of disabled people, we have included a description of the medical model and the social model. It is very important that if society is to include and protect the rights of disabled people that they operate under the SOCIAL MODEL. The following description of the two models was written by Professor Richard Reiser, a disabled person working in the UK, advocating for inclusion of disabled people.

The Medical Model

The 'medical model' of disability sees the disabled person as the problem. We are to be adapted to fit into the world as it is. If this is not possible, then we are shut away in some specialised institution or isolated at home, where only our most basic needs are met. The emphasis is on dependence, backed up by the stereotypes of disability that call forth pity, fear and patronising attitudes.

Usually the focus is on the impairment rather than the needs of the person. The power to change us seems to lie within the medical and associated professions, with their talk of cures, normalisation and science. Often our lives are handed over to them.

*Other people's assessments of us, usually non-disabled professionals, are used to determine where we go to school, what support we get and what type of education; where we live; whether or not we can work and what type of work we can do and indeed whether or not we are born at all, or are even allowed to procreate. Similar control is exercised over us by the design of the built environment presenting us with many barriers, thereby making it difficult or impossible for our needs to be met and curtailing our life chances. **Whether in work, school, leisure and entertainment facilities, transport, training and higher education, housing or in personal, family and social life, it is practices and attitudes that disable us.** Powerful and pervasive views of us are reinforced in the media, books, films, comics, art and language. Many disabled people internalise negative views of themselves that create feelings of low self-esteem and achievement, further reinforcing non-disabled people's assessment of our worth. The 'medical model' view of us creates a cycle of dependency and exclusion, which is difficult to break.*

'Medical model' thinking about us predominates in schools where 'special educational needs' are thought of as resulting from the individual who is seen as different, faulty and needing to be assessed and made as normal as possible. If people were to start from the point of view of all children's right to belong and be valued in their local school we would start by looking at 'what is wrong' with the school and looking at the strengths of the child.

The Social Model

This second approach is based on the 'social model' of disability thinking which views the barriers that prevent disabled people from participating in any situation as what disables them. The 'social model' arises from defining impairment and disability as very different things.

Impairment and chronic illness exist and they sometimes pose real difficulties for us. The Disability Movement comprises those disabled people and their supporters who understand that they are, regardless of their particular impairment, subjected to a common oppression by the non-disabled world. We are of the view that the position of disabled people and the discrimination against us are socially created. This has little to do with our impairments. As a disabled person you are often made to feel it's your own fault that you are different. The difference is that some part, or parts, of your body or mind are limited in their functioning. This is an impairment.

This does not make you any less of a human being. But most people have not been brought up to accept us as we are. Through fear, ignorance and prejudice, barriers and discriminatory practices develop which disable us. The understanding of this process of disablement allows disabled people to feel good about themselves and empowers us to fight for our human rights.

***The disabled people's movement believes the 'cure' to the problem of disability lies in the restructuring of society.** Unlike medically based 'cures', which focus on the individual and their impairment, this is an achievable goal and to the benefit of everyone. This approach, referred to as the 'social model', suggests those disabled people's individual and collective disadvantage is due to a complex form of institutional discrimination as fundamental to our society as sexism, racism or heterosexism.*

In addition to this, the obsession with finding medically based cures distracts us from looking at causes of either impairment or disablement. In a worldwide sense, most impairments are created by oppressive systems - hunger, lack of clean water, exploitation of labour, lack of safety, problems with ecology, drug or alcohol misuse, child abuse and wars. Clearly, this thinking has important implications for our education system, particularly with reference to primary and secondary schools. Prejudicial attitudes toward disabled people and, indeed, against all minority groups, are not inherited. They are learned through contact with the prejudice and ignorance of others. Therefore, to challenge discrimination against disabled people, we must begin in our schools.

Our fight for the inclusion of all children, however 'severely' disabled, in one, mainstream, education system, will not make sense unless the difference between the 'social' and the 'medical' or individual model of disability is understood.

This Disability Guide is written from the position of the social model. I believe that disabled people are important and valid individuals in our society. I believe that disabled people can give positive things to society if they are supported to achieve their Rights. I believe that disabled people, parents and communities need to understand disability and the discrimination that disabled people face if we are to adapt the system in Kyrgyzstan to ensure that all disabled people achieve their rights.

I want my child to be normal

This is one of the most difficult issues for families to face. One of the first very normal reactions for families is to see the disability as a fault and they feel that they want to fix it. Parents may feel guilty that it was something they did during pregnancy, or ashamed and that people may feel that there is something wrong with them. Some parents feel that it is a punishment by God or a curse. In our opinion none of these things are true. Disabled people are born in every culture and in cultures that welcome and support difference and diversity can make positive contributions to families and communities,

However parents who want their child to be normal often can have high expectations of specialists to cure their child. In reality the disability will not be cureable, unless it is a small physical defect that with surgery or medical intervention can be corrected, although the child can and will develop physically, emotionally, psychologically and intellectually with the right rehabilitation programmes.

It is very important for families to think about how their need for the child to be normal impacts on the child. If a child is to be happy about themselves then they need to feel accepted for who and how they are. If a parent is wholly driven on making the child perfect then a child will begin to have very negative feelings about themselves and their abilities. This may impact on their behaviour, personality, self image, and ability to develop. They may begin to think that my family will only love me if I'm perfect – or start to feel a burden on the family.

Don't forget that disabled children give a positive new dimension to the family and bring with themselves a positive contribution.

It is very important that disabled children know that their family accepts them from who they are, because often others in society don't. They also need support to understand why they may be different to other children. They may ask painful questions like "Why am I not beautiful like other girls?" "Why do people stare at me?" "Why does nobody like me?" "Why am I not normal?"

Parents need to prepare themselves and their child for these difficult moments and the only way to do that is to build a positive sense of self in the child, be honest with the child, make sure the child has a role in the family and acknowledge and build on the child's strengths.

Talking with other parents who have in the same place and also have a disabled child, often helps.

Having said all of this you should still strive for the best possible rehabilitation services for your child – that is very important. But make sure that you are doing it to support your child's development - not for your need that your child is perceived as normal.

The following words were spoken by a disabled woman about her views that disabled people need to be accepted as they are if they are to achieve a sense of self worth.

"When a mother says that she loves her child "in spite" of the child's disability, she is saying that she does not love the disabled part of her child. When an organisation says: 'see the person, not the wheelchair' they are being asked to ignore something that is central to disabled people's experience. And when our achievements are applauded as "overcoming all odds" the disabled part of us is being denied and diminished. Valuing us as people should not mean ignoring the things about our bodies that make us different. In asserting our rights we also want to take pride in ourselves. We cannot do this unless this pride incorporates the way we are different."

(Jenny Morris, 1992)

Should my child go to an Internat?

Making a decision to place a child in an internat is a very personal and difficult one. In this section we want to provide balanced information that may help a family come to a decision about whether it is the best thing to do for a child and their family. Families may place their children in internats for a number of reasons including:

- Feelings of not being able to cope with the responsibility of a disabled child
- Being advised by specialists and or family and friends that it is the best option
- To secure some level of education for the child
- To stop the breakdown of their marriage
- Financial and practical reasons
- Families are unable to cope with a child's emotional and behavioural problems

Often families experience some level of grief and or loss when they find out they have a disabled child. They may feel overwhelmed by the situation and placing a child in an internat may seem

like the only solution. However, there are other options and it is important that families understand the positive and negative issues regarding internat provision.

Positive Factors

There are some very good reasons why some families choose to place their child in an internat. They may feel that their child can get better services in an internat and that their needs will be met. Some of the positive factors of internats include:

1. The child receives basic care that is provided for by the state. Their basic needs should be met within internats. (Families in poverty may believe that the child's basic needs can be met better in the internat than in the family.)
2. If it is an internat with educational provision then a child will be provided with some level of education.
3. They provide homes for children who may otherwise be abandoned or neglected.
4. Sometimes internats have access to other specialists that can support the child's development.
5. Living within a group may help the child be stimulated to learn.
6. Special internats for children with specific disabilities such as deaf young people may have better resources in terms of equipment and trained staff.

Negative Factors

Many Countries have started on programmes of de-institutionalisation for example UK, Lithuania, Holland, Georgia etc. Kyrgyzstan is currently talking about the issues of de-institutionalisation between ministries. The United Nations Children Rights Convention (1989) identifies that the best place for children to be brought up is in the family – and actually states this as a right. This is because International research has proved that internats have negative outcomes for most children. These negative outcomes include:

1. Trauma for the child. Children removed from their families before the age of 6 are the age group that have the worst outcomes of institutionalisation. They often suffer significant psychological and emotional delay due to the trauma of separation from families and continue to have attachment problems throughout their lives. This is due to the lack of one significant carer for the child at a key stage of their development. Often staff has large numbers of children to care for and individual needs may be unmet.
2. The child may find it impossible to be re-integrated back into society after being removed and excluded from communities for a long period of time. They become institutionalised for life.
3. The educational outcomes for children in internats are often low and this impacts on their future ability to work and live in society.
4. Bullying and abuse is more likely to happen when children are living in group settings and is much more difficult to identify and stop.
5. The child can become emotionally detached from the family and communication methods and relationships may breakdown.

6. Disease and illness may spread more quickly in a group setting that may have health implications for children.

Although there are negative outcomes for disabled children in internats the quality of care and education varies greatly from internat to internat. Parents also may feel that because community services are only presently being developed that internats still offer the best opportunities for their child. If you are trying to make the decision about whether you should put your child in an internat the following advice may help.

- 1. Make your decision in your own time based on all of the facts.**

Sometimes parents can feel pressured to make a decision when they first give birth to a disabled child. They may be by doctors or nurses in the maternity house who bring forms for you to sign, by family members or friends. However, you may be being given a very negative view of your child and his future without the balanced facts.

- 2. Find out about different Internats and the quality of these**

As we said before it is important to look at the quality of internats that you send your child to. Have a visit and see how they work, make sure you get the opportunity to:

- a) See, talk and play with the children there. Do they look happy? Do they interact well with adults and each other? Are they clean and well fed? Do they have any obvious bruises or injuries? Are they healthy without skin and or other diseases?
- b) Talk to specialists. Do they talk fondly of the children? Do they enjoy their work? Can they give examples of positive work they have done with the child? Do they seem to have emotional attachment with the child?
- c) Talk to the Director. Do they see the importance of family remaining involved in the child's life? Do they have emotional attachment to the children? Do they have a good practical understanding of what is happening in their internat?
- d) Contact parents of other children who attend the internat to find out their experiences.

- 3. Look at Community Based Provision**

Have a look at what other opportunities and services are in your area. It may be that new services are being developed that might meet the needs of your child and family. These types of services are being developed more and more.

If you do make the decision to place your child in an internat then you should still maintain links with your child. A child, no matter how severely disabled, always needs the love that can be found in a family. By doing the following things you can support your child and keep them as part of your family:

1. Bring your child home at weekends and holidays. Or if possible they could attend the internat on a day time basis, like an ordinary school.
2. Visit your child often. Bring them small presents from home and photographs that they can show to their friends and teachers.
3. Talk to specialists about your child's education. Ask to see examples of their work and display some at home so that your child can see when they visit that you are proud of them.
4. Find out which specialists your child likes the most and who are their friends. This enables you to communicate about these people on visits and shows that you are interested in things and people that are important for your child.

5. Make sure you use the same communication methods with your child as in school. This may mean you learning sign language or using communication books. Investing your time in learning your child's communication will maintain your relationship.
6. Talk to your child about why they live in an internat. Many children may feel that you don't love them like their siblings or that you have abandoned them. By explaining your reasons you can show that you made a decision because you love your child.
7. If you notice a change in your child's condition or mood then bring it to the immediate attention of the specialists. A change in weight, appetite, mood, development can be caused due to unhappiness or stress. It is important to address these issues early.
8. Teach your child about what to do if they are bullied or hurt by another person. Always believe and help your child if they say that another person has hurt them. Some children may make up stories but this is often because there is another underlying reason and this must always be taken seriously.

Some internats discourage families from remaining involved with their children. They claim that contact with parents upsets and distresses children. However, often children are able to express their emotions when you visit which is much healthier than being locked inside. A good internat will value to importance of families involvement and actively encourage families to remain involved with their child.

General information about different Disabilities

The following information about different disabilities is a general guide. Not every child with these diagnoses behaves or develops in these ways. This information should only be used as a guide. It is important to never under-estimate what your child can do – although understanding limitations of your child due to their impairment is also important.

Learning Disabilities

The term 'learning disabilities' is used to describe a large number of impairments. Some impairments labelled as learning disability may have a definite diagnosis such as Down's Syndrome, although for many children it is impossible to diagnose why and what caused a child to be born or develop learning disabilities.

This can be very difficult for parents as it is often important for parents to understand why their child is disabled before they can come to terms with it.

A person is defined as having learning disabilities if they have a delay or incomplete development of psyche that impacts on the development of:

- Thinking
- Speech
- Social functions
- Fine movements

People can have learning disabilities in different severities. Within a modern classification learning disabilities are categorised in 4 levels although not all of these criteria can be applied to every child in each category.

Many parents and specialists confuse a psychological/ learning disability with a disabled child experiencing psychological problems.

A psychological/ learning disability is an impairment or delay in psychological development due to the disabling condition of a child. However, many physically disabled children who do not have psychological disabilities may experience psychological problems. Often these problems stem from discrimination, feeling excluded and not accepted or not receiving sufficient stimulation.

This does not make a physically disabled child psychologically disabled. It means that we need to provide sufficient support in order to help a child with any psychological problems they may have.

Mild Learning Disabilities

Speech

The speech is practically intact, though may be poorly developed. Vocabulary increases slowly, passive vocabulary dominates over an active one (e.g. showing with signs, gestures and emotions rather than speech) often the phonetics of many sounds can be wrong.

Self Service Skills

Often children can fully develop self service skills including eating, washing, dressing and toileting.

Fine Movements

These are generally not severely affected and children can acquire practical skills and may go on to be good at carpentry, sewing, cooking etc. However, some fine movements of fingers may be affected although this would not generally impact on being to complete basic tasks.

Academic Skills

Children may have problems learning, although specially adapted curriculum's can achieve good results. They may need additional support in schools and additional lessons with defectologists and other specialists to improve learning ability.

Social Skills

Children often develop good social skills and can form relationships well. They may need support when they come to have families of their own in terms of financial management, support and bringing up their own children.

Moderate Learning Disability

Speech

Speech is usually delayed in development and vocabulary may be limited, consisting mainly of everyday words. Pronunciation may be difficult to understand but children understand common speech when directed to them, and can respond appropriately.

Social Skills

The emotional responses of children are usually better developed than the intellect. They have skills of sympathising and caring for others, but at the same time can be indifferent to people they don't know. However, moderately learning disabled children can establish good relationships and communicate well with others if given the correct stimulation. Usually these children need substantial support if they were to live independently.

Self service skills

Self service skills develop slowly but with specialist support children can develop a wide range of self care abilities.

Academic

Many children with moderate learning disabilities can learn simple writing, reading and counting skills. However, they need to be provided with special curriculum and methodologies to do this. Teachers need to understand how children can learn and simplify tasks.

Work

They can also learn how to undertake different jobs including house cleaning, washing linen, office work, animal care and agricultural work. Each person is an individual and their individual skills and talents must be identified in order for them to find the right kind of job for them.

Fine Movements

The ability to move develops more slowly in these children and movements may be awkward and they may mimic repetitively.

Severe Learning Disabilities

Speech

Speech is very limited, children may pronounce simple words and understand basic instructions. However, with specialised speech programmes they can develop short phrases.

Social Skills

Emotional reactions may be poor although people will often show emotional affection to those they have sustained contact with – although this affection may be unstable and disappear if a child is not in close contact with this person.

Behaviour

This may be either very quiet and withdrawn or very excitable and boisterous.

Self Service Skills

They develop these very slowly and often require many times of repetition and re-visiting techniques.

Academic

A mainstream curriculum is not suitable for children with severe learning disabilities. However, they can with adapted programmes develop different skills. They often do not develop the ability to read and write but can express themselves in other ways such as drawing, modelling, drama, dance and practical lessons.

Fine Movements

There is often delay in physical development. Movements may be limited, awkward and sometimes chaotic. Children will begin to walk and move at a later age.

Profound Learning Disabilities

Speech

Speech is usually absent, although sometimes children utter separate sounds. Often children don't understand others speech and therefore cannot react to it – or only react to intonation.

Reactions

Reactions to light sound and taste and sometimes even to pain can be weak. Others have exaggerated eating reflexes and eat everything they can find – earth, rags, excrements.

Behaviour

Often behaviour depends on their physiological needs. Maybe quiet when they are dry, have been fed and are satisfied but upset and or agitated when they are in an unsatisfactory condition. Children may be aggressive towards themselves or other people.

Self Skills

With very intensive programmes some children can develop some self care skills.

Academic

Although children are unable to follow a curriculum they do require intensive education to improve practical skills and to stimulate their thinking.

What is Down's syndrome?

Down's syndrome is a genetic condition (i.e. something you are born with, which is present in the baby from the moment of conception) caused by the presence of an extra chromosome. Chromosomes are tiny particles, which are present in every cell in every tissue in our bodies. They carry the 'blueprint' for all the characteristics we inherit. This blueprint is carried in the form of a coded message in a chemical substance called DNA. There are 23 pairs of chromosomes in each cell, hence 46 altogether. One of each pair comes from the father, one from the mother. In 1959, a French geneticist, Professor Jerome Lejeune, discovered that Down's syndrome was caused by the presence of an extra copy of chromosome 21, making 47 chromosomes in all. A 'syndrome' is a collection of signs or characteristics. The name 'Down' comes from the English doctor, John Langdon Down, who first described the syndrome in 1866, nearly 100 years before the extra chromosome was discovered. Everyday in the UK, between one and two babies are born with Down's syndrome, (figures unavailable in Kyrgyzstan) which means that one baby in 1000 has the condition. People with Down's syndrome all have a certain degree of learning disability (mental handicap). The degree of disability varies from person to person and it is impossible to tell at birth what that degree will be.

What causes Down's syndrome?

As yet, we do not know what causes the presence of extra number 21 chromosome. It can come from either the mother or the father. The most common type of Down's syndrome, Standard Trisomy 21 (also known as Primary Trisomy 21 or Regular Trisomy 21), occurs because of an unusual cell division which has produced either an egg or a sperm with 24 chromosomes instead of 23. When this egg or sperm fuses with an ordinary egg or sperm, the first cell of the developing baby has 47 chromosomes instead of 46, and all that baby's cells will have 47 chromosomes. There is no way of predicting whether a person is more or less likely to make eggs or sperm with 24 chromosomes. We know that babies born to older mothers have a higher chance of having Down's syndrome, but we do not know why.

Could we have prevented our baby having Down's syndrome?

It is important to remember that you are not to blame for your baby having Down's syndrome. Nothing you did before or during pregnancy has caused it. It occurs in all races, in all social classes and in all countries throughout the world. It can happen to anyone.

Does it mean that any further children we might have will also have Down's syndrome?

Standard Trisomy 21 is not hereditary. However, once you have had one baby with Down's syndrome your chances of having another child with the condition are increased. Overall this chance is between 1 in 100 and 1 in 200, which is considerably less than the chance of, say, having twins 'out of the blue'. When thinking about your next pregnancy it would be helpful to talk to a genetic counsellor who could talk things through with you in some detail.

What does the extra chromosome mean for our baby?

All people with Down's syndrome share some certain physical characteristics, though not every child with the condition has every characteristic. Your baby will have inherited physical characteristics from both of you, just like any other of your children, as well as sharing some of the common signs of Down's syndrome. Your baby is unique. Some parents wonder if there is a link between the number of these physical characteristics and the future development of their new baby. In fact, there is no way at this early stage of predicting the level of ability of your child. The extra chromosome means that your baby will be slower to reach her milestones and will have a certain degree of learning difficulty, but most children with Down's syndrome can, given the right support, learn to walk and talk, ride a bike and read and write, in fact to do most of the things other children do. It's just that their development is usually delayed.

What are the common signs of Down's syndrome?

- Your baby may have looser muscles and joints than other babies. This will improve as she gets older.
- She may have lower than average birth weight and put on weight at a slower pace than other babies.
- Babies with Down's syndrome often have eyes that slant upward and outward. Their eyelids often have an extra fold of skin (epicanthic fold) which appears to exaggerate the slant. This does not mean that there is anything wrong with the eyes. They just look different.
- The back of your babies' head may be flatter than average.

- Many babies with Down's syndrome have a single crease which runs right across the palm of the hand. Doctors often look for this characteristic crease, as a sign that a baby may have Down's syndrome. However, some babies who do not have Down's syndrome also have a crease like this.

All babies are different from each other and the same is true of babies with Down's syndrome. This means that in some babies the characteristic signs of Down's syndrome are fairly easy to recognise soon after birth, whilst others may look and behave little differently from other babies. However, experienced doctors and midwives are usually very good at picking up subtle differences, which suggest that a blood test should be done to check the chromosomes.

Will our Down's Syndrome baby have health problems?

Chest and sinus problems

Babies and young children with Down's syndrome tend to be prone to chest and sinus infections but, thanks to better medical knowledge and care, such infections are no longer as serious as they used to be.

Feeding problems

Some babies with Down's syndrome seem to lack the strength and determination to feed in the early days. Some may be slow to sort out the complicated co-ordination necessary to suck, swallow and breathe at the same time and they splutter and choke a bit. These problems often settle down during the first two weeks. If you want to breast-feed, but find that your baby can't cope in the early days it may well be that if you keep your milk going he will soon sort himself out and take to breast-feeding. You may have chosen to bottle-feed your baby for whatever reason and many babies with Down's syndrome find it easier to feed from the bottle. It will not harm your baby to have formula milk. The important thing is that you and your baby should be as contented as possible! When you begin to feed your baby it is worth trying to hold her fairly upright to feed and check first that the tongue is not sticking to the roof of the mouth. For a baby to suckle and get adequate milk the nipple or teat must be ON the tongue (not under it). Specially adapted teats are available to help babies who have difficulty feeding. Do not hurry the feed. Babies with Down's syndrome often feed very slowly, so do not stop too quickly. Your baby may fall asleep at intervals. If this happens in the middle of a feed, try tickling his cheeks, chin and feet.

Temperature control

The body's heat-regulating mechanism does not always work well in early life. It is therefore important that the baby's bedroom is not cold (18°C is ideal), and there are no draughts. Overheating can be hazardous for all babies, however, and it is important that they do not get too hot through over-wrapping when indoors. Humidifying the air will help your baby to breathe more freely, too.

Skincare

Your baby's skin may be very dry. Massage him with a little baby oil and put some in the bath water. A little moisturising cream, for example E45 cream, unperfumed cold cream or olive oil

rubbed gently on the skin every day should prevent drying and crying. Keep an eye out for allergic reactions. Your doctor or pharmacist can help with alternatives. You may be able to obtain some creams on prescription.

Tongue control

You may need give your baby particular attention to help control her tongue. Playing games, pulling faces and making noises etc. will assist your child to exercise face and tongue muscles and also help with early sounds and speech. Try to avoid a blocked nose, which would encourage open-mouth breathing and protruding tongue. Humidifying the air in the baby's room will help to prevent a dry blocked nose. Making a game of pushing in the tongue over and over again will help!

Heart problems

About one in three children born with Down's syndrome has a heart defect. Some heart defects are quite minor, such as heart murmurs; some defects are severe, requiring medication and/or surgery.

Your baby's heart will be one of the things that a paediatrician will check at her first neonatal examination, and, if there is any doubt about a heart defect being present, then further tests will be made to make sure everything is as it should be. However, heart defects are not always picked up by these tests when a baby is very small, so your paediatrician will continue to make regular checks in the first year or so for any signs of a defect. If you are ever worried about anything - ask your doctor!

How will having a baby with Down's syndrome affect the rest of the family?

Having a baby with Down's syndrome in the family will require a period of readjustment. You may feel under more pressure to do things with your baby to help her development than you would have felt with any other baby. Take time to get to know the baby as part of the family. Your baby with Down's syndrome will have his own personality and characteristics just like your other children.

What does the future hold for our child?

During the first few weeks, many parents ask:

- What will be available for my child when she is older?
- What kind of financial provision can we make for our child's future?

Children with Down's syndrome can grow up to live long and fulfilled lives. Provided they are allowed the opportunities they need to develop self-help skills and independence. People with Down's syndrome can thrive well in to their fifties, facing many of the challenges we all encounter: school, further education, work and a home of one's own, although this can be difficult in Kyrgyzstan with its lack of services. Many children with Down's syndrome, in European countries, are now being integrated successfully into mainstream schools. The majority of children / adults with Down's Syndrome will continue to require extra support from their families and services for all of their lives. Available provision differs from area to area and the situation is always changing. There does seem a real lack of services for adults with Down's Syndrome and many parents worry about what

will happen to their children when they are no longer around to look after them. (See I want my Child to Have a Home When he is an adult page)

Introduction to cerebral palsy

This part of the guide describes cerebral palsy, its causes and some of the terms used to describe its effects. Cerebral palsy is a condition which affects movement, posture and co-ordination. These problems may be seen at or around the time of birth or may not become obvious until early childhood. Cerebral palsy is a wide-ranging condition and can affect people in many different ways.

Cerebral palsy is more common than generally realised. Currently, it is believed that about one in every 400 children is affected by the condition (figures not available in Kyrgyzstan). Cerebral palsy can affect people from all social backgrounds and ethnic groups.

It is often not possible for doctors to give an exact reason why part of a baby's brain has been injured or failed to develop, as there may be no obvious single reason why a child has cerebral palsy. Causes of cerebral palsy can be multiple and complex. Some studies suggest that cerebral palsy is mainly due to factors affecting the brain before birth. Known possible causes include:

- Infection in the early part of pregnancy
- Difficult of premature birth
- A cerebral (brain) bleed. This is more common following premature or multiple birth.
- Abnormal brain development
- A genetic link – although this is quite rare.

Cerebral palsy affects the messages sent between the brain and the muscles. There are three types of cerebral palsy, they are spastic, athetoid (or dyskinetic) and ataxic and generally relate to which part of the brain has been affected. The effects of cerebral palsy vary enormously from one person to another, with some people having a combination of two or more types.

It is often difficult for a doctor to predict accurately how a young child with cerebral palsy will be affected later in life. Cerebral palsy is not progressive, i.e. it does not become more severe as the child gets older, although some difficulties may become more noticeable.

There is no cure for cerebral palsy. If children are positioned well from an early age and encouraged to move in a way that helps them to improve their posture and muscle control, they can be supported to develop and achieve more independence for themselves. There are also a number of therapies, which may be beneficial for some individuals.

Spastic cerebral palsy

'Spastic' means 'stiff' and this form of cerebral palsy causes the muscles to stiffen and decreases the range of movement in the joints. It is the most common form of cerebral palsy and can affect different areas of the body. Generally someone with spastic cerebral palsy has to work hard to walk or move. If the person is only affected on one side of their body the term used to describe this is 'hemiplegia'. If their legs are affected but their arms are unaffected or only slightly affected this is known as 'diplegia'. If both arms and both legs are equally affected, then the term used is 'quadriplegia'.

Athetoid (or dyskinetic) cerebral palsy

People with athetoid cerebral palsy make involuntary movements, because their muscle tone changes rapidly from floppy and loose to tense and still, in a way they cannot control. Speech can be hard to understand as there may be difficulty controlling the tongue, breathing and vocal cords. Hearing problems are also common.

Ataxic cerebral palsy

People with ataxic cerebral palsy find it very difficult to balance. They may also have poor spatial awareness, which means it is difficult for them to judge their body position relative to other things around them. Ataxia affects the whole body. Most people with ataxic cerebral palsy can walk but they will probably be unsteady. They may also have shaky hand movements and irregular speech. It can be difficult to state what type of cerebral palsy a person has as they may have a combination of two or more types. It is important to bear in mind that no two people with cerebral palsy are affected in the same way. Some have cerebral palsy so mildly that its effects are barely noticeable. Others may be extremely affected and require help with many or all aspects of daily life.

Other associated difficulties

Other difficulties and medical conditions may occur more commonly in people with cerebral palsy but just because a person has cerebral palsy does not mean that they will also have other difficulties. However, it may help you to be aware of some of them:

- Children with cerebral palsy may have problems with constipation or sleeping. The doctor or health visitor should be able to offer advice about this.
- People with cerebral palsy may have problems with speech and associated difficulties in chewing and swallowing. They may also have problems understanding the spoken word. A speech and language therapist may be able to offer advice.
- Some people with cerebral palsy may also have epilepsy. Often medication can help control this.
- Some people with cerebral palsy may have difficulty distinguishing and comparing shapes. This is to do with visual or spatial perception, which is about a person's ability to interpret what they have seen and not a problem with their eyesight.
- People with cerebral palsy may also have some form of learning difficulty, making them slow to learn. The difficulties can be mild, moderate or severe. There may be a 'specific learning difficulty' or problems with a particular activity such as reading, drawing or arithmetic because a specific area of the brain is affected.
- It is important to remember that even someone severely physically affected by cerebral palsy may have average or above average intelligence.

Why is My Child Deaf or Hearing Impaired?

There are many reasons why a child can be born deaf or become deaf early in life. It is not always possible to identify the reason. You may be offered further tests to establish the cause of your child's deafness. Your child's audiologist will be able to tell you where you can get further information about these tests.

This section lists many of the common reasons. There is information on possible causes that happen before a child is born and those that happen at birth or afterwards. There is also information on different types of deafness.

Causes before birth (pre-natal causes)

Around half of the deaf children born in Europe every year are deaf because of a genetic reason. Deafness can be passed down in families even though there appears to be no family history of deafness. For about 70 per cent of these deaf children no additional problems will occur. For the remaining 30 per cent of deaf children the gene involved may cause additional disabilities or health problems.

Deafness can also be caused by complications during pregnancy. Illnesses such as rubella, cytomegalovirus (CMV), toxoplasmosis and herpes can cause a child to be born deaf. There also is a range of medicines, known as ototoxic drugs, which can damage the hearing system of a baby before birth.

Causes in infancy (post-natal causes)

As with pre-natal causes there are a number of reasons why a child may become deaf after they are born. Being born prematurely can increase the risk of being deaf or becoming deaf.

Premature babies are often more prone to infections that can cause deafness. They may also be born with severe jaundice or experience a lack of oxygen at some point. Both of these can cause deafness.

In early childhood there is a range of things that can be responsible for a child becoming deaf. Infections like meningitis, measles and mumps can cause deafness. Ototoxic drugs, used to treat other types of infections in babies, can also be a cause.

Occasionally deafness is caused by an injury to the head or exposure to loud noise. These can cause damage to the hearing system.

What are the different types of deafness?

There are two main types of deafness:

- Sensory-neural deafness, or nerve deafness as it is sometimes called, is a hearing loss in the inner ear. This usually means that the cochlea in the inner ear is not working effectively.
- Conductive deafness means that sound cannot pass through the outer and middle ear into the inner ear. This is often caused by blockages such as wax in the outer ear, or fluid in the middle ear (glue ear). Glue ear is a very common condition, especially in pre-school children.

It is possible for children to have a combination of sensory-neural and conductive deafness. It is also possible to have a permanent conductive deafness, but this is very rare.

Very few deaf children have no useful hearing. Most deaf children can hear some sounds at certain frequencies and loudness, and with the use of hearing aid they are often able to hear more sounds.

Why are there different tests?

There are a number of different ways of measuring hearing. The audiologist decides which tests to use. This depends on how old your child is and for which type of deafness the audiologist is testing.

The tests measure how much hearing your child has, and help to identify the type of deafness. If your child is very young, the audiologist may have to do a series of tests before they are able to give you all the information.

There are different degrees of deafness, which are often described as mild, moderate, severe or profound. Hearing levels are often described in terms of decibels. When you next visit the hospital with your child for a hearing test, ask the audiologist to explain the results to you, and request a copy of the results to keep. It is important for you to know the level of your child's hearing, as you may be asked for this information by teachers or others working with your child.

Communication with Deaf Children

Learning and wanting to communicate is something that occurs naturally in all children. If your child is still very young, you have time to learn to communicate with your child at the same time as they are learning to communicate with you. If your child is older, they may already be developing a way of understanding you. For example, many children develop skills in lipreading without ever being taught.

We learn about and understand the world around us through communication with others. Communication also allows us to develop good personal and social skills as we become adults.

Deaf children need to have access to fluent language so that they can develop good communication and language skills. This could be either through spoken language or sign language or both together.

The following can help a deaf child to develop good communication and language skills:

- early and accurate identification of deafness
- correct fitting of the most suitable hearing aid, where needed
- positive acceptance, support and commitment from you as parents
- you as parents having access to information, advice and support
- the whole family having the opportunity to learn about deafness

It can be difficult to make a decision about which communication method is best for your child, so it is important that you are given clear and balanced information about all the options available

Communication tips

Below are some points to remember when you are communicating with your deaf child. These apply to children who use either oral skills or sign language and to those children who use a combination of both.

- Make sure that you have your child's attention before starting a conversation.
- Make sure you are facing them and maintaining good eye contact. Try to be on the same level as them and allow some space for signing or lip reading, ie a distance between yourself and your child of about one to two metres.
- Use a well-lit room and don't have your back to a window, as this creates a shadow and makes it difficult to read facial expressions or lip read.

- Speak clearly, naturally and at a normal pace. Don't shout, as it can appear to your child that you are angry and it also distorts lip patterns.
- Try to make sure that background noise is kept to a minimum. Children with hearing aid, cochlear implants or those children with a mild or unilateral deafness who do not use hearing aid may find it particularly difficult to pick out what is being said. A room that is carpeted or that has curtains will help to cut down the effects of noise in a room.
- If your child does not use sign language, it is still helpful to use your hands and facial expressions to gesture and support what you are saying.
- Don't eat or smoke while speaking or block the view of your face. Keep beards or moustaches trimmed and also remember that glasses and sunglasses can make it difficult to maintain eye contact.
- When in a group speak one at a time. It is helpful if the speaker raises their hand before talking so that your child knows who is speaking.
- Make sure you let your child know when there is a new topic of conversation.
- Some words or signs may not be easily understood, in which case use a different word or sign with the same meaning. Be careful of using unusual words.
- Pause between sentences and check that your child has understood you, and that you have understood him/her. Encourage him/her to stop you if they don't understand what the conversation is about.

Blind and Visual Impairments

How this guide can help you

This guide provides answers to some of the initial questions you may have - what are the causes of sight problems? What can blind people see? How do people get around or read? By providing facts and information, this guide aims to change the way we think about blindness.

People with sight problems come from all sorts of backgrounds and lead all sorts of lives. Each person is affected in a way that is individual to them - it is not the same experience for everyone.

Many people with sight problems lead full and independent lives. Some may need assistance with certain tasks and may have to adapt their daily lives, but this is possible and very often achieved with success. Organisations such as Blind and Deaf Society can offer help and assistance where needed.

What does "sight problems" mean?

When we say "people with sight problems", we are describing the full range of people who have uncorrectable sight loss. Sight loss is a very common cause of disability in Kyrgyzstan, and is associated with old age more than any other disability. The older you become, the more likely you are to have a sight problem.

What are the common causes of sight problems?

Some people are born with sight problems whilst others may inherit an eye condition, such as retinitis pigmentosa, that gets gradually worse as they get older. Some people may lose their sight as the result of an accident, whilst illness can lead to conditions such as diabetic retinopathy.

Some ethnic groups are at a high risk of acquiring certain eye conditions. For example, people of Afro-Caribbean origin are particularly susceptible to glaucoma.

In the poorer countries of the world millions of people suffer due to the effects of what should be easily controlled diseases. Trachoma, for instance, is an eye condition caused by poor hygiene and inadequate sanitation. Yet it is responsible for 15 per cent of the world's blindness.

How can sight problems be prevented?

Many thousands of people have an eye disease but don't know it. An eye test every two years can help identify potentially life-threatening illness and detect eye conditions before sight is affected. By the time your vision starts to get worse, it could be too late to save your sight.

What can people with sight problems see?

Being blind does not always mean that a person is living in total darkness. Forty-nine per cent of blind and eighty per cent of partially sighted people can recognise a friend at arm's length.

Other people will be affected by eye conditions in different ways: some will have no central vision or no vision to the sides; others may see a patchwork of blank and defined areas, or else everything may be seen as a vague blur.

Glaucoma can result in tunnel vision, where all side vision is lost and only central vision remains. Diabetic retinopathy can cause blurred and patchy vision. Macular degeneration can lead to a loss of central vision whilst side vision remains.

However, don't forget that people are affected by eye conditions in different ways. You should not assume that you know what someone can see just because you know what eye condition they have.

Fact file

Being blind does not mean total darkness. You might think that if you shut your eyes you are temporarily blind. However, if with your eyes shut you were to turn your head towards a window, you would detect a minimal perception of light. Around one fifth of people who are blind have this level of vision or lower. The rest will have some useful sight.

Can it be difficult getting around?

Many people with sight problems get around independently. They may use their remaining vision and/or a mobility aid, such as a white cane or a guide dog. Other people may need the assistance of someone with sight. Some people could also have additional disabilities which make it difficult to get around.

Fact file

Canes are an essential mobility aid for many blind and partially sighted people. Long canes are moved from side to side to identify obstacles in a person's path. Symbol canes are used purely to identify someone as having a sight problem.

What can help people to get around safely?

In a familiar place, a person with sight problems will often be able to get around safely by using their memory of the surroundings and any remaining sight they have.

If you visit somebody in their home or at their place of work, remember not to move things around or leave things in places that could cause an accident. This also applies if somebody with a sight problem is visiting you.

The way public areas, buildings and public transport are planned is also very important. Certain design features can help enormously such as:

- well-positioned, easy to read signage, ideally with a tactile or braille element
- tactile paving - paving slabs with raised bumps - which warns people of hazards, such as road crossings
- clear reliable announcements of stops on public transport.

Fact file

Badly parked cars; notice boards standing outside shops and trees and plants overhanging the pavement are examples of easily avoidable potential hazards to someone with a sight problem.

How do people with sight problems read?

The ability to read written information is crucial to our independence and ability to do everyday things such as shop or travel. However, often information is not available to people with sight problems in a way that they can read it.

Many partially sighted people can read ordinary, printed information if it is well designed. Text of a good size (such as 14 point print,) and good contrast between the colour of the text and the background can help. Some people use what is known as large print, which can be any size from 16 point upwards.

There are systems of reading by touch such as braille. Audio-tape is a popular method of accessing information, used mostly for leisure, and CD-Roms are being used more frequently by those with the ability to use a computer.

How can computers help?

If blind and partially sighted people have access to computers either in the workplace or at home, what would be a big help. People with sight problems can obtain information from a computer in different ways:

- closed circuit televisions (CCTVs) enlarge the text on screen until it is large enough to read
- computerised speech systems read text from the screen to the user
- text on screen can be converted into braille that is displayed directly onto a specially adapted keyboard and read by touch.

These methods can be used to access the huge amount of information available on the internet. If a web page is well designed, people with sight problems can read them. For example, images or pictures should have a text description attached.

Fact file

Audio description can help people with sight problems enjoy television, videos, DVDs or the theatre. Visual information such as scenery and body language is described aurally to complement the usual programme sounds.

When supporting a visually impaired or blind person:

- introduce yourself and make sure the person knows you are speaking to them
- talk directly to them and not through a third party
- if you are going to guide them, let them take your arm, don't grab theirs
- point out kerbs and steps as you approach them and say whether they go up or down
- mention any potential hazards that lie ahead and say where they are
- if you are guiding someone into a seat, place their hand on the back of the seat before they sit down, so they can orientate themselves
- don't walk away without saying you are leaving.

Fact file

Many people with sight problems leave their home rarely, if at all. One of the main reasons for this is fear of crossing the road. Good design features such as tactile paving at crossings and visual, audible and tactile signals telling you when to cross, are all helpful but are often not available.

Developing Your Child's Self Care Skills:

When you have a child with a visual impairment it is very tempting to try and do everything for them. However it is crucial for your child to develop independence and you can help them do this in the following way:

- Involving them in the design of furniture in rooms so that they can orientate themselves within the home safely.
- Buying or making clothes that are easy to fasten e.g. big buttons, elastic waists etc.
- Sewing "markers" into clothes that children can learn which way round clothes should be worn.
- Encouraging them to cook and make drinks for themselves first with supervision and then more and more independently.
- Building relationships with local shops so that they understand your child's condition and will provide the necessary support when they go to buy things.
- Encourage your child to take pride in their appearance – support them to brush their hair, put on make-up, arrange their clothes (if age and culture appropriate) and give them feedback on how beautiful and attractive they look. It is very important to visually impaired people, like all people, that they look their best.
- Spending time with your child outside helping them to orientate themselves, explaining where things are so that children are provided with a visual map of where they live and other places in their community.

It can be very frightening for a parent to allow a visually impaired child to be independent – but you are providing them with skills that are essential as they grow into adulthood.

About deafblindness

Deafblindness (or dual-sensory-impairment) is an unique disability which brings enormous challenges to the individual and those who support them.

Deafblindness has many causes. It affects people of all ages in different ways, and no two deafblind people are the same.

Many people will not be totally deaf and totally blind but will have some remaining use of one or both senses. Others will also have additional physical and/or learning disabilities as well.

It is important to tailor communication to the individuals skills and strengths. An individual form of communication may need to be developed with each child these may include:

Clear Speech

Speaking clearly is one of the most effective and common ways of communicating with people who have acquired hearing loss.



Block

Block is a manual form of communication where words are spelled out on to the palm of the deafblind person's hand.



Deafblind manual alphabet

Also known as finger-spelling, the Deafblind Manual Alphabet is a method of spelling out words onto a deafblind person's hand.



Sign Language

Sign Language is a language in its own right, which uses hand signs and facial expressions as a visual form of communication.



Visual frame signing

Visual frame signing is a form of Sign Language signed within the person's remaining field of vision.



Hands on signing

With hands on signing, the deafblind person follows the signs by placing his hands over those of the signer and feeling the signs formed.



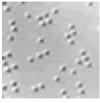
Makaton

A basic form of sign language



Tadoma

People who use tadoma will place their hands on the speaker's lips or throat to feel the vibrations.



Braille and Moon

Both these methods are ways of producing text to enable it to be read by touch.



Objects of reference

Some people who are deafblind learn to use objects which symbolise a particular significant activity

In developing a form of communication with your child you may require specialist help. A good specialist will work from your child's strengths and help develop communication that meets the families needs. Touch is a very important form of communication for deaf blind people. A young deafblind child in particular will need lots of support and communication through touch to reassure them.

What is Spina Bifida and hydrocephalus?

Spina Bifida is a neural tube defect that happens in the first month of pregnancy when the spinal column doesn't close completely. The effects of Spina Bifida are different for every person. Up to 90 percent of children with the worst form of Spina Bifida have *hydrocephalus* (fluid on the brain) and must have surgery to insert a "shunt" that helps drain the fluid—the shunt stays in place for the lifetime of the person. Other conditions include full or partial paralysis, *bladder* and bowel control difficulties, *learning disabilities*, *depression*, *latex allergy* and *social and sexual issues*.

There are different types of Spina Bifida:

Occulta

Often called hidden spina bifida, the spinal cord and the nerves are usually normal and there is no opening on the back. In this usually harmless form of spina bifida, there is a small defect or gap in a few of the small bones (vertebrae) that make up the spine.

There may be no motor or sensory impairments evident at birth, subtle, progressive neurologic deterioration often becomes evident in later childhood or adulthood.

In many instances, spina bifida occulta is so mild that there is no disturbance of spinal function at all. Occulta can be diagnosed at any age.

Meningocele

The protective coatings (meninges) come through the open part of the spine like a sac that is pushed out. Cerebrospinal fluid is in the sac and there is usually no nerve damage. Individuals may suffer minor disabilities. New problems can develop later in life.

Myelomeningocele

This occurs when the meninges (protective covering of the spinal cord) and spinal nerves come through the open part of the spine. This is the most serious type of spina bifida, which causes nerve damage and more severe disabilities.

Your child may need additional support from specialist particular those who support motor and physical development. They will develop rehabilitation programmes that will help your child maximise their potential.

What is Hydrocephalus?

Hydrocephalus is the abnormal build up of cerebrospinal fluid in the ventricles of the brain. In most instances, hydrocephalus is a lifelong condition in that the patient is treated rather than "cured." Presently, there is no known way to prevent or cure hydrocephalus and shunts are the primary method to treat hydrocephalus. The one-way calibrated shunt system was introduced in 1952.

Treatment by shunting the cerebrospinal fluid (CSF) to another area of the body, generally allows patients to lead full and active lives. There are different kinds and models of shunting systems. Although, shunts were a major medical breakthrough, there are problems that still remain unsolved in the treatment of hydrocephalus, such as shunt obstruction and infection.

An overwhelming majority of newborns with hydrocephalus will have a normal life span and normal or even superior intelligence. In addition, they will enjoy normal activities and be useful members of society. However, there are complications associated with hydrocephalus with learning disabilities being one of the most prevalent.

In most cases, hydrocephalus is not hereditary.

Types of Hydrocephalus

Hydrocephalus is a condition that can exist during one of two stages. Hydrocephalus can also be either *congenital*, where the condition is present at birth or detected soon thereafter; or *acquired*, where the condition is acquired as the result of infection, head trauma, brain tumours, cysts, etc.

Forms of Hydrocephalus

Hydrocephalus exists in two forms; *communicating* (non-obstructive hydrocephalus) caused by inadequate absorption of CSF when the ventricular pathways are not obstructed; or *noncommunicating* (obstructive hydrocephalus) caused by blockage in the ventricular pathways through which CSF flows.

Effects of Hydrocephalus

Hydrocephalus involves accumulation of cerebrospinal fluid (CSF) in the ventricles of the brain, with an increase in the pressure inside the head.

There are two sources of this pressure. One is that of the CSF itself, but a much higher pressure is produced by the heart in order to pump blood to the brain. If the CSF pressure rises, it eventually interferes with the blood supply to the brain, depriving it of oxygen and glucose which it needs in constant amounts to continue to function. Initially this causes tiredness, irritability and drowsiness, but if it progresses then loss of consciousness will result as the brain begins to shut down.

The immediate effects of this interference with the blood supply disappear if the CSF pressure is returned to normal, such as by ventricular tap or insertion of a shunt. However, in most cases the process has been continuing for some time before diagnosis of hydrocephalus is made. During this time the interference with the blood supply leads first to a 'dying back' of the very fine blood vessels in the brain. Even this process is largely reversible if prompt action is taken, but at this time there is often insufficient clinical evidence to suspect hydrocephalus. The next stages involve progressive damage to the actual nerve cells in the brain and to their eventual destruction, and this cannot be reversed.

Because of the areas of the brain most affected, functions associated with thought and learning, as well as with co-ordinated skilled movement, begin to deteriorate. The precise effects differ between individuals and are further complicated by other abnormalities, as well as by the pre-existing degrees of ability and personality of each person affected. It is not surprising therefore that while, for instance, learning disorders are common amongst those with hydrocephalus, their exact effects vary considerably.

Much is said and written about intelligence, and particularly about IQ (intelligence quotient) in people with hydrocephalus. In fact this is far more complicated, and a good deal less informative, than many believe. The IQ is made up of several components which can be thought of as verbal and non-verbal, or performance-related tests. People with hydrocephalus generally score better on verbal IQ than on performance IQ and this is thought to reflect the distribution of nerve damage in the brain as described above. Certainly, during periods of rising CSF pressure, such as in untreated cases or when a shunt is blocked, the effect on performance IQ is more marked. Generally speaking, people who have had hydrocephalus since birth or childhood have, as a group, a lower average IQ than a comparable group without hydrocephalus, but it is important to realise that there is a wide range in each group, and some people with hydrocephalus have very high scores.

The practical implications of these features of hydrocephalus are that there may be subtle problems of co-ordination of hand movements with what the person sees, as well as a degree of clumsiness, which make it difficult to perform certain tasks or do certain jobs. With regard to learning in the home or to education in school, there may be real problems with concentration and reasoning which require a sympathetic but skilled approach. For instance, it will often be necessary to teach simple everyday tasks like getting out of bed, washing one's face, dressing and going downstairs as separate short items rather than all at once, and to keep them consistent and repetitive. This does not indicate 'stupidity', but is caused by damage to the nerves in the brain which normally allow us to learn very quickly how to do a complex series of things. Much can be done to help, and professional advice should be sought where needed.

Psychological development in children and adolescents with hydrocephalus may proceed normally, but sometimes the changes associated with puberty (breast development, body hair growth etc) appear much earlier than expected, and the intrusion of psychological aspects of sexual development into a mind which is emotionally still very immature can cause distressing problems. Again, specialist advice should be sought if necessary. Other effects of hydrocephalus may also be seen, and some of these are difficult to explain. For instance, some people are very seriously distressed by every-day noises such as vacuum cleaners or washing machines.

One effect of raised CSF pressure may be seen in the eyes, and this is why your doctor sometimes looks for 'papilloedema'. This is caused by pressure on the blood supply to the back of the eye. It is important to realise that it may not always be present, even when the pressure is high. If CSF pressure remains high for too long, damage to the optic nerves can become permanent resulting in blindness, though fortunately nowadays this is uncommon. Another appearance, particularly in babies, is the so-called 'sunset' eye sign, where the eyes are fixed in a downward position. This is due to CSF pressure affecting important nerves running from the brain which control eye movement.

If untreated the rise in CSF pressure can cause other serious problems in the brain, unrelated to blood supply. Many of our vital functions, such as heartbeat, breathing etc, are controlled from the brain stem, a structure joining the spinal cord to the brain. Very high CSF pressure can compress this sufficiently to cause the heart and breathing to stop. Once again, this is uncommon as signs of raised pressure are usually recognised before this. A similar problem might sometimes arise, particularly in those with spina bifida, due to compression of the cerebellum, a part of the brain lying at the back of the head. This can also give rise to breathing, speaking and swallowing difficulties.

About 1:3 children with hydrocephalus will develop epilepsy which will be treated by a neurologist.

Reading a catalogue of the effects of hydrocephalus, such as I have produced here, can be very alarming. However, it should be realised that some people with hydrocephalus may have very few of these problems, and hopefully none of the more serious ones. Also, many of those which I have described are found either in untreated hydrocephalus or when the treatment fails, and when successful treatment has been promptly introduced they often improve or sometimes disappear. On the other hand, the more subtle learning and reasoning problems are usually present in some degree and are very important where a child's development and education are concerned.

There can be learning difficulties associated with hydrocephalus such as problems with learning difficulties, behaviour, motivation and visual problems:

Children with hydrocephalus often exhibit behaviour problems that are mistakenly attributed to naughtiness (or disruptive tendencies).

Of course children with hydrocephalus can be naughty as much as any other child and the difficulty often lies with sorting which cause the perceived bad behaviour has.

If the child's behaviour deteriorates rapidly, think shunt; if the onset is insidious, it is likely to be due to the damage caused by the hydrocephalus.

Epilepsy

What is epilepsy?

The brain is made up of millions of nerve cells that control the body's functions, senses and thoughts. The nerve cells do this by passing electrical signals to each other. In some people, this process may suddenly be interrupted and this can cause a seizure (sometimes called 'fit' or 'attack'). If a person has **more than one such seizure**, they may have epilepsy.

The type of seizure a child has depends on which area of the brain is affected. Some seizures involve convulsions, or strange and confused behaviour, but others, such as absences, may be

harder to recognise. Some may be unnoticeable to everyone except the child experiencing the seizure.

Despite the appearance of some seizures, the child is not in pain.

Causes of seizures and epilepsy

Epilepsy can begin at any age, but often develops in childhood. There are a number of causes of seizures in children.

Some people develop epilepsy as a result of the brain being injured in some way, perhaps as a result of a severe head injury, difficulties at birth or a serious infection which affects the brain, such as meningitis. Epilepsy with a known cause such as these is called **symptomatic epilepsy**.

However, in the majority of cases of epilepsy, no cause can be found and this is called **idiopathic epilepsy**.

Epilepsy is described as **cryptogenic** when no cause has been found for the seizures but one is suspected.

Diagnosis and Treatment

How is epilepsy diagnosed?

Seizures can occur for many reasons, not just epilepsy. Other types of seizures include febrile convulsions, breath-holding attacks and syncope (fainting).

If your child has more than one seizure, your Doctor will usually refer them to a specialist for diagnosis. Often the doctor makes the diagnosis using an eyewitness description of the seizure and other information about the child's medical history. However, to help with diagnosis, a number of investigations may be used. For example:

- a physical examination and in some cases a blood test.
- a CAT (computerised tomography) or MRI (magnetic resonance imaging) scan
- an EEG (electroencephalogram)

These tests will not diagnose epilepsy, but they may help provide additional information to help establish the cause of the seizures. Normal results from these tests do not rule out a diagnosis of epilepsy.

The tests are painless but younger children or children with learning disabilities may be given a light anaesthetic to help them relax and stay still.

What is a syndrome?

If a child has been diagnosed with an epileptic syndrome, their seizures have a particular group of characteristics that occur together.

Seizures classified within a syndrome have a typical pattern, a typical age when they start and produce specific EEG recordings. The syndrome may also follow a definite pattern of progression.

If a syndrome is described as 'benign' it is expected to respond well to anti-epileptic medication and may go away as the child grows up. Some syndromes are more difficult to treat and may also involve learning or behavioural problems or some physical difficulties.

Who is responsible for my child's treatment?

Professionals who may be involved in a child's medical care include:

- a paediatrician - children's doctor
- a paediatric neurologist - who specialises in the brain and nervous system

When a young person reaches the age of 16 to 18, they may start seeing a specialist who treats adults. The GP is responsible for a child's care between appointments with the specialist.

How is epilepsy treated?

Most children with epilepsy are treated with anti-epileptic medication. This cannot cure epilepsy but aims to prevent seizures from occurring. Once the right drug or combination of drugs is found, many people on medication become seizure-free.

Like all drugs, those for epilepsy may cause side effects in some people. These often wear off after a time or may be minimised by adjusting the dosage. If you or your child are concerned about any aspect of the medication you may want to talk to your pharmacist or doctor. Medication should not be changed or stopped without first consulting the doctor.

Another possible treatment option for children whose seizures are not controlled by medication is the high fat, low carbohydrate **ketogenic diet**.

This diet is usually recommended by the child's consultant and a referral made to an appropriate dietician. The child's response to the diet will then be closely monitored by both the consultant and dietician.

For a few children whose epilepsy cannot be controlled by medication, surgery may be an option.

What else can be done to prevent seizures?

Some children's seizures occur in response to certain triggers such as stress, over-excitement, boredom or lack of sleep. It may be helpful to keep a diary of seizures to see if a pattern emerges. If this is the case, avoiding these situations as far as possible may help to make seizures less frequent.

Can my child's epilepsy change with age?

As a child gets older, their seizures may change in type and frequency. Some girls find that their seizures change when their periods start, becoming more frequent around the time of their period. The doctor may discuss making changes to their medication to help at this time.

Some children outgrow their epilepsy by their mid to late teens. This is known as spontaneous remission. Types of epilepsy that typically do not continue into adult life include **benign rolandic epilepsy** and **absence epilepsy of childhood**.

If a child has not had a seizure for a number of years, the doctor may discuss the possibility of gradually reducing the level of medication, and eventually withdrawing the drugs altogether.

How will epilepsy affect my child's life?

Leisure activities

Most children with epilepsy can participate in the same activities as other children. Simple precautions can help make activities such as swimming and bike riding safer for people with epilepsy.

The vast majority of people with epilepsy are able to go to discos, use computers and watch television at no increased risk of having a seizure. Photosensitive epilepsy is when seizures are triggered by certain frequencies of flashing lights. It is usually detected during an EEG test and is often treatable with medication. If your child has photosensitive epilepsy they may need to take extra precautions.

Learning

Most children with epilepsy have the same intelligence and learning potential as other children. However, having frequent seizures may interrupt your child's everyday learning.

Management of a seizure varies depending on the type of seizure that occurs. It can be useful to talk to the school about your child's epilepsy, so that people can recognise and help to manage their seizures. Some seizure types may be very subtle and difficult to detect, and can go unnoticed.

Some children with epilepsy also have learning disabilities that may originate from the same cause as the epilepsy. These children may need extra help at school or may go to a school that provides specialist teaching and support.

Behaviour

For many children having epilepsy and taking anti-epileptic drugs will have no effect on their behaviour. Behaviour changes and problems can occur in all children regardless of having epilepsy and for many may be part of growing up.

Some people notice a change in their child's mood or behaviour; for example becoming moody, irritable or withdrawn. Having epilepsy does not change someone's character, however some children may be responding to how they are feeling about having epilepsy. It may help if the child can discuss these feelings with someone and that they are not treated differently from their siblings or friends.

In a few children, irritable or hyperactive behaviour may be a side effect of anti-epileptic drugs. If you are concerned about changes in your child's behaviour, it may be helpful to discuss this with their doctor.

Who needs to know about my child's epilepsy?

The decision of who and when to tell about the epilepsy lies with you and your child. It may be helpful to tell people who spend time with your child so that they feel prepared if a seizure does occur.

Will my other children develop epilepsy too?

There may be a genetic element to epilepsy, especially if no structural cause can be found for the seizures. Included in our genetic make up and passed on from parent to child is a level of resistance to seizures, also called **seizure threshold**. A person with epilepsy may have a low seizure threshold. However, having this low threshold does not mean that seizures will always occur. Other children in a family may have a similar threshold but will not necessarily go on to have seizures or develop epilepsy.

Adolescence

Like all teenagers, young people with epilepsy will probably want to make their own choices about their lives. When doing this it helps to be informed about the effects these new activities might have on their epilepsy.

Late nights, experimenting with alcohol and recreational drugs and emotional stress are often typical parts of teenage life. In some people, these may make seizures more likely to occur.

It might be important to discuss the issue of contraception as certain anti-epileptic drugs can make methods such as the contraceptive pill less reliable.

Some teenagers find epilepsy difficult to live with, particularly if they are experiencing frequent seizures or side effects from the medication. They may decide to stop visiting the doctor or to stop taking their medication. It may help teenagers to discuss their feelings and choices with someone they feel comfortable with, who can encourage them to take control in making decisions about their epilepsy.

Your feelings as a parent

A diagnosis of epilepsy can give rise to a range of emotions for everyone affected. It can take time to come to terms with a diagnosis and what effect this may have on life. How you feel about a diagnosis may also change over time.

Reading about a condition or talking to someone about it can sometimes help.

The following information relates to people with epilepsy

Anyone can have a single seizure at some point in their life. This can happen if the circumstances are appropriate. This is not the same thing as having epilepsy, which means having **a tendency to experience recurrent seizures** that originate in the brain.

What is a seizure?

An epileptic seizure (often called a fit and sometimes an attack, turn or blackout) happens when ordinary brain activity is suddenly disrupted. The seizures described here are epileptic and arise from the brain.

Epileptic seizures can take many forms, since the brain is responsible for such a wide range of functions, including:

- personality
- mood
- memory

- sensations
- movement
- consciousness

Any of these functions may be temporarily disturbed during the course of a seizure.

Some very young children have convulsions when there is a sudden rise in their body temperature and this is called a 'febrile convulsion'. This is not classified as epilepsy.

How can seizures be described?

There are many different types of seizures. Not all of them involve convulsions. When naming seizures, it is important to use terms which describe what is happening during the seizure and to avoid terms such as 'mild' or 'major' which do not describe the event.

A person with epilepsy can experience more than one type of seizure. The frequency, length and pattern of seizures tends to be fairly constant for each person, although it may change in the longer term. If a person becomes aware of any changes to their seizures it may be helpful to have a review of their epilepsy and its treatment.

Partial seizures

During partial seizures the disturbance in brain activity begins in or involves one part of the brain. These seizures are sometimes known as 'focal' seizures. A person's experiences during the seizure will depend on which part of the brain is being affected.

- In simple partial seizures consciousness is not impaired. The seizure may be confined to either rhythmical twitching of one limb or part of a limb, or to unusual tastes or sensations such as pins and needles in a specific part of the body. Simple partial seizures sometimes develop into other sorts of seizures and so they may be referred to as a 'warning' or 'aura'.
- Complex partial seizures differ from simple partial seizures in that consciousness is affected and so the person may have limited or no memory of the seizure. The seizures may be characterised by a change in awareness as well as automatic movements such as fiddling with clothes or objects, mumbling or making chewing movements, or wandering about and general confusion. The person may respond if spoken to. Complex partial seizures most often involve the temporal lobes of the brain, in which case the person may be said to have 'temporal lobe epilepsy', however they can also affect the frontal, parietal and occipital lobes.
- For some people either of these partial seizures may spread to involve the whole of the brain. This is called a secondarily generalised seizure and the person will lose consciousness. If this spread is rapid, the person may not be aware of the partial seizure onset.

Generalised seizures

In these seizures the whole of the brain is involved and consciousness is lost. They often occur with no warning and the person will have no memory of the event. The seizure may take one of the following forms:

- The most recognised type of seizure is the generalised tonic-clonic convulsive seizure, sometimes called a 'grand mal' seizure. In the first part of the seizure the person becomes

rigid and may fall. The muscles then relax and tighten rhythmically causing the person to convulse. At the start of the seizure the person may bite their tongue or cry out. Breathing may become laboured and they may be incontinent. After the seizure the person may feel tired, confused, have a headache and may need to rest to recover fully.

- In tonic seizures there is general stiffening of the muscles without rhythmical jerking. The person may fall to the ground with consequent risk of injury but generally recovery is quick.
- Atonic seizures, also known as drop attacks. These involve a sudden loss of muscle tone, causing the person to fall. Again, there is consequent risk of injury but recovery is generally rapid.
- Myoclonic seizures involve brief and abrupt jerking of one or more limbs. These often happen within a short time of waking up, either on their own or with other forms of generalised seizure.
- Absence seizures occur most commonly in children and are sometimes referred to as 'petit mal'. The person experiences a brief interruption of consciousness and becomes unresponsive. They may appear 'blank' or 'staring' usually without any other features, except perhaps for a fluttering of the eyelids. Absence seizures often last for only a couple of seconds and as they are subtle they may go unnoticed.

Some seizure patterns may not fit into any of the above categories or may include elements of different seizures. These are called unclassifiable seizures.

Some people experience seizures only during sleep. As these will usually be at night they are called nocturnal seizures. These seizures could also occur during the day if the person were to fall asleep. This does not describe the form that the seizures take, only the time when they occur.

Status epilepticus

Most seizures last for the same amount of time for each person and usually stop of their own accord. However, in some circumstances seizures are not self-limiting and do not stop, or one seizure occurs after another with no recovery period in between. This situation is known as status epilepticus. This can occur in any type of seizure, however it is a medical emergency requiring medical intervention if it occurs with a tonic-clonic seizure.

An ambulance should be called if the seizure lasts for 2-3 minutes longer than normal, or if it lasts for more than 5 minutes and the usual duration of a seizure is not known.

What to do when a seizure happens

Convulsive seizures

Seizures cannot be stopped or altered, so the best thing to do is to follow these guidelines.

During the seizure:

- Try to stay calm
- Check the time to monitor how long the seizure lasts, as prolonged seizures may require emergency medical help
- Prevent others from crowding round
- Put something soft under the person's head - such as a jacket or cushion - to prevent injury.
- Only move the person if they are in a dangerous place, for example at the top of the stairs or in the road. Move things away from them if there is a risk of injury.

- Do not attempt to restrict or restrain the convulsive movements as this may cause injury to the person or yourself
- Do not put anything in the person's mouth. There is no danger of them swallowing their tongue during a seizure and you may damage their teeth or your own fingers
- Check that any tight clothing around the neck is loosened, including necklaces.

Once the convulsions have stopped:

- Roll the person onto their side into the recovery position
- Wipe away any excess saliva and if breathing is still laboured, check that nothing is blocking the throat such as dentures or food
- Do all you can to minimise any embarrassment. If the person has been incontinent deal with this as sensitively as possible
- Stay with the person giving reassurance until they have fully recovered
- Do not give the person anything to eat or drink until they are fully recovered.
- Provide the opportunity for the person to lie and rest in a quiet dark place after recovery.

Convulsive seizures can be frightening to watch, but the person having the seizure is not in pain and will have little or no memory of what has happened.

At the start of the seizure the person may cry out as the air from the lungs is expelled through the voice box. During the early part of a seizure breathing may stop and the person may go slightly blue. This looks alarming but is to be expected until normal breathing resumes later on. The person may also bite their tongue.

Medical help should be called if:

- Someone has injured themselves badly in a seizure
- They have trouble breathing after a seizure
- One seizure immediately follows another without recovery in between

The seizure continues for longer than usual (they may be carrying a card which says how long their seizures usually last) or the seizure lasts more than five minutes and you do not know how long they usually last

Emotional and Behavioural Disorders

Some disabled children may also have emotional and behavioural disorders. There may not be a clear reason as to why a child may have these difficulties it may be due to:

- Learning disability
- Reaction to medication
- Lack of self confidence and self esteem
- Lack of stimulation

Whatever the cause it can be very difficult caring for a child with emotional and behavioural disorders. Families may require specialist support and behavioural programmes.

Examples of problematical behaviour may include:

Hyperactive/inattentive

The hyperactive child is disruptive in the classroom setting: he won't get on with his set work and his behaviour will make sure that his peers' work suffers too.

The inattentive child may get up from his seat and wander around: he may hum, tap his fingers etc.

Both problems are often associated with poor short term memory and may improve if strategies to overcome this are employed. These strategies can include reminders (verbal and written), setting work to be done in short bursts, trying to increase the child's memory span by "memory games".

Verbal aggression and swearing

The swear words seem to "come from nowhere" and where the child hears them is often a mystery. However, once the child finds the attention he gets and the effect that swearing has on others, he will use it as a powerful tool to get his own way.

Verbal aggression - threats, demands etc. - is also distressing and often shocking, again is a way of controlling adults.

Bizarre behaviour

A good example is the boy that laughs loudly for long periods (sometimes several hours) with no trigger and often in the middle of the night. He has no explanation, why should he? To him this is quite usual. The parents are powerless to stop it.

Role play

Where the child really believes that he is the person whose persona has taken on e.g. the boy who is an airline pilot and talks jargon obviously learnt from films - "Chocks away", "Roger and out" etc.

Threatened suicide

This is, fortunately, uncommon in children and usually involves long, convoluted accounts of how he is going to commit suicide - mostly unrealistic. For example "I shall jump out of the window and run across the road under a car and then I'll go to the railway line and throw myself under a train and then I'll drown in the river and you'll be really really sorry".

Parents, quite rightly, become very worried: the threat of suicide (in children) is rarely carried out but your doctor needs to be aware.

Obsessions

Children may be obsessive with objects and shapes (often circles), colours (particularly primary colours) and people.

Children may be overprotective towards their chosen obsession and unable to share: they may become aggressive to people they are obsessed with and this can increase if this person is seen to prefer another child or even if they just talk to another child.

As you can imagine, life can be difficult if the child is obsessed with a family member (particularly mother) or a teacher as the situation will, of course, arise when this person has to be shared. The concept of sharing people's attention needs to be talked through with the child (and often repeated)

Robotic behaviour

The child may exhibit complicated rituals at home, at school, at play. Everything has to be done in the same order by the same person: it can start insidiously with more components gradually included.

No sense of danger

The child will walk off the top of climbing frames, step off roundabouts when he has finished playing etc. Just as important, "stranger danger" needs frequent reinforcement - "frequent" may mean daily for some children.

Temper tantrums

These can affect children of all ages. There is often a 'trigger' which starts this mode of behaviour but this can be so subtle that it is difficult to identify - often a change of routine, a perceived insult, a change in weather. Commonly, the child will have to continue the tantrum until it reaches a natural end: they seem incapable of stopping the behaviour despite the parents/cares applying 'usual' distractions or discipline.

Mood swings

"From angel to devil" in a matter of minutes. This can be a daily (or many times daily) occurrence and can appear to be cyclical in both boys and girls: keeping a diary will help note the regularity.

Social isolation

Many children have no friends of their own age and this can be due to many factors; but remember, some children like being on their own.

Inappropriate sexual behaviour

Even young children may make sexual remarks, may touch other people sexually and may even make sexual approaches. If nothing is done (and parents do find it embarrassing and shocking and difficult to address), this can carry on into adulthood.

The need to follow a pattern of behaviour to its conclusion

Unless you can identify the trigger which provokes the behaviour, you will not stop the child until he is ready to stop.

It is as though, once started, the child has to progress through certain stages and is powerless to interrupt the process or allow it to be interrupted.

Lying

All children lie. Children with emotional and behavioural problems may believe that what they say is the truth however improbable or outrageous the lie is. Unlike most children, they will, however, often change their story when challenged.

Manipulating - people and situations

Children soon learn the best method to get their own way and how to maintain their position of dominance in the family. Using their condition is so easy and so effective!

Once a behavioural problem has been identified, look for possible reasons

- does the behaviour fluctuate? Is it cyclical? If yes, keep a diary and show it to the psychologist.

Then:

- is there associated epilepsy? If yes, check medication for side effects.
- has any medication been started or stopped?
- is your child taking unprescribed (even herbal) or “social” drugs?
- has puberty arrived? Remember some disabled children have precocious (early) puberty.
- and is the behaviour related to short term memory problems? Spatial awareness? Concentration?

Now, look at the time of day:

- is the child feeling harassed? Are you hurrying him? (Try to allow more time if this is the case).
- has the daily routine changed?
- do you think your child’s blood sugar is low. (Glucose drink or glucose tablets may help).
- is the child tired?

Has there been a change in circumstances?

- New school?
- New sibling?
- New step parent?
- Even new furniture can affect some children.

Stress may be a factor:

- exams or test of any kind.
- arguments with friends.
- appointment with doctor/dentist/ optician etc.

Regular behavioural changes first thing in the morning or at the end of the day may signify pressure changes.

What do we do?

There are no simple solutions - if only there were! However, a few simple suggestions may help:

- parents and school need to work together and appear united.
- do not discuss your anxieties in front of the child or his siblings.
- make eye contact with the child when you are speaking to him.
- give one instruction at a time; ask one question at a time. Keep it all in simple steps.
- acknowledge good behaviour.

- be positive.....when you can.
- avoid difficult situations which may trigger poor behaviour. This could involve a different route to school to avoid road works etc. Or you could try diversionary tactics i.e.“look at the aeroplane”.

Try to discuss what has happened after the event

- What triggered the behaviour?
- Why?
- What could you or the parent have done to help?

Avoid:

- threats e.g. “if you do that you will get no dinner”. The child will only retain the last part of the sentence and will therefore assume that he will not be eating tonight.
- using sarcasm e.g. ”oh well done” - it will be taken literally.
- ridiculing the child.
- verbal overload: a long lecture is a waste of your time and energy. The child will soon lose interest or will forget what he is being lectured about.

Introduction to Autism

Although it was first identified in 1943, autism is still a relatively unknown disability. People with autism are not physically disabled in the same way that a person with cerebral palsy may be; they do not require wheelchairs and they 'look' just like anybody without the disability. Due to this invisible nature it can be much harder to create awareness and understanding of the condition.

Because an autistic child looks 'normal' others assume they are naughty or the parents are not controlling the child. Strangers frequently comment on this 'failing'.

What is autism?

Autism is a lifelong developmental disability that affects the way a person communicates and relates to people around them. Children and adults with autism have difficulties with everyday social interaction. Their ability to develop friendships is generally limited as is their capacity to understand other people's emotional expression.

People with autism can often have accompanying learning disabilities but sometimes a person with autism is extremely smart, but can only use his intelligence on one specific topic or issue. But everyone with the condition shares a difficulty in making sense of the world.

There is also a condition called Asperger syndrome, which is a form of autism used to describe people who are usually at the higher functioning end of the autistic spectrum.

"Reality to an autistic person is a confusing, interacting mass of events, people, places, sounds and sights. There seems to be no clear boundaries, order or meaning to anything. A large part of my life is spent just trying to work out the pattern behind everything." (**A person with autism**)

What are the characteristics of autism?

People with autism generally experience three main areas of difficulty; these are known as the triad of impairments.

- **Social interaction** (difficulty with social relationships, for example appearing aloof and indifferent to other people)
- **Social communication** (difficulty with verbal and non-verbal communication, for example not fully understanding the meaning of common gestures, facial expressions or tone of voice)
- **Imagination** (difficulty in the development of interpersonal play and imagination, for example having a limited range of imaginative activities, possibly copied and pursued rigidly and repetitively).

In addition to this triad, repetitive behaviour patterns and resistance to change in routine are often characteristic.

What causes autism?

The exact cause or causes of autism is/are still not known but research shows that genetic factors are important. It is also evident from research that autism may be associated with a variety of conditions affecting brain development which occur before, during, or very soon after birth.

Diagnosis

The earlier a diagnosis of autism is made, the better the chances are of a person receiving appropriate help and support.

Can people with autism be helped?

Specialist education and structured support can really make a difference to the life of a person with autism, helping to maximise skills and achieve full potential in adulthood.

Communication and interaction

Communication happens when one person sends a message to another person either verbally or non-verbally. Interaction happens when two people, for example, an adult and a child, respond to one another - a two-way communication.

Most children with an ASD (autistic spectrum disorder) will have difficulty interacting with others. This is because in order to be successful at interaction the child needs to respond to others when they are approached by them or be able to initiate interactions. Although many children with an ASD are able to do this when they want something, they tend not to use interaction to show people things or to be sociable.

It is important to remember that communication and interaction do not have to involve the use of language and speech. Many children with an ASD are delayed in their use of language and shy away from using speech. Therefore, other methods of communication need to be established before speech and language will follow.

What is Asperger syndrome?

As soon as we meet a person we make judgements about them. Just by looking we can guess their age or status, and by the expression on their face or the tone of their voice we can tell immediately if they are happy, angry or sad and respond accordingly.

Not everyone has this natural ability. People with Asperger syndrome find it more difficult to read the signals which most of us take for granted. As a result they find it more difficult to communicate and interact with others. This leaflet explains the characteristics of Asperger syndrome and what can be done to help those affected.

Asperger syndrome is a form of autism, a condition that affects the way a person communicates and relates to others. A number of traits of autism are common to Asperger syndrome including:

- difficulty in communicating
- difficulty in social relationships
- a lack of imagination and creative play

However, people with Asperger syndrome usually have fewer problems with language than those with autism, often speaking fluently, though their words can sometimes sound formal or stilted. People with Asperger syndrome do not usually have the accompanying learning disabilities associated with autism; in fact, people with Asperger syndrome are often of average or above average intelligence.

Because of this many children with Asperger syndrome could enter mainstream school and, with the right support and encouragement, can make good progress and go on to further education and employment.

Key characteristics

Asperger syndrome shares many of the same characteristics as autism. The key characteristics are:

Difficulty with social relationships

Unlike the person with 'classic' autism, who often appears withdrawn and uninterested in the world around them, many people with Asperger syndrome want to be sociable and enjoy human contact. They do still find it hard to understand non-verbal signals, including facial expressions, which makes it more difficult for them to form and maintain social relationships with people unaware of their needs.

Difficulty with communication

People with Asperger syndrome may speak fluently but they may not take much notice of the reaction of the people listening to them; they may talk on and on regardless of the listener's interest or they may appear insensitive to their feelings.

Despite having good language skills, people with Asperger syndrome may sound over-precise or over-literal - jokes can cause problems as can exaggerated language, turns of phrase and metaphors. A person with Asperger syndrome may be confused or frightened by a statement like 'she bit my head off'. In order to help a person with Asperger syndrome to understand you, keep your sentences short - be clear and concise.

Lack of imagination

While they often excel at learning facts and figures, people with Asperger syndrome find it hard to think in abstract ways. This can cause problems for children in school where they may have difficulty with certain subjects such as literature or religious studies.

Special interests

People with Asperger syndrome often develop an almost obsessive interest in a hobby or collecting. Usually their interest involves arranging or memorising facts about a special subject, such as train timetables, Derby winners or the dimensions of cathedrals.

With encouragement interests can be developed so that people with Asperger syndrome go on to study or work in their favourite subjects.

Love of routines

People with Asperger syndrome often find change upsetting. Young children may impose their routines, such as insisting on always walking the same route to school. At school, they may get upset by sudden changes, such as an alteration to the timetable. People with Asperger syndrome often prefer to order their day according to a set pattern. If they work set hours then any unexpected delay, such as a traffic hold-up, or a late train, can make them anxious or upset.

These are the main features of the condition, but because every person is an individual, these characteristics will vary greatly and some may be demonstrated more strongly than others.

What causes Asperger syndrome?

The causes of autism and Asperger syndrome are still being investigated. Many experts believe that the pattern of behaviour from which Asperger syndrome is diagnosed may not result from a single cause. There is strong evidence to suggest that Asperger syndrome can be caused by a variety of physical factors, all of which affect brain development - it is not due to emotional deprivation or the way a person has been brought up.

Is there a cure?

Asperger syndrome is a developmental condition affecting the way the brain processes information and there is no 'cure'; children with Asperger syndrome become adults with Asperger syndrome. Much can be achieved to make life less challenging with appropriate education and support.

With time and patience people with Asperger syndrome can be taught to develop the basic skills needed for everyday life, such as how to communicate appropriately with people.

The importance of early diagnosis

Because the condition of people with Asperger syndrome is not as marked as those with autism, they may not be diagnosed for a long time. This can mean that their particular needs may go unrecognised and parents may blame themselves, or worse still blame their child for their unusual behaviour.

What does the future hold?

At present, there are few facilities specifically for children with Asperger syndrome. Some children are in mainstream schools where their progress depends on the support and encouragement of parents, carers and teachers. Some children with Asperger syndrome go to specialist schools for children with learning disabilities, which often is not the best place for them.

Because their disability is often less obvious than that of someone with autism, a person with Asperger syndrome is, in a sense, more vulnerable. They can, sadly, be an easy target for teasing or bullying at school.

As they get older, they may realise that they are different from other people and feel isolated and depressed. People with Asperger syndrome often want to be sociable and are upset by the fact that they find it hard to make friends.

But the future for people with Asperger syndrome does not have to be bleak. Adults with Asperger syndrome can and do go on to live fulfilling lives, to further education and employment and to develop friendships.

In the workplace, people with Asperger syndrome can offer a great deal - punctuality, reliability and dedication - though informed and understanding employers and colleagues are essential.

Part 2 Communication and Development

How can I communicate with my disabled child?

Many different disabled children have communication barriers. Children with learning disabilities often need additional support in communication, as do children with physical disabilities who may find speech problematic or even impossible. The types of disabilities that may need additional communication support include:

- Learning Disabled people (Down Syndrome, Autism, Aspergers, etc.)
- Physically Disabled people (Cerebral Palsy, Deaf and Hearing, Blind and visually impaired, etc.)

This section will hopefully enable you to understand a little bit more about the problems that disabled people have in communication and provide you with useful tips to support the development of communication.

Understanding the communication of a disabled child

Often parents and carers of disabled children feel that they are unable to communicate and interact with their child and are unsure of how to do so. The child may appear not to hear what is said to them, fail to respond to their name and/or be indifferent to any attempts of communication that are made. The use of everyday opportunities and play can encourage communication and interaction in a disabled child.

The way in which the child communicates needs to be observed in order to develop their communicative strengths and needs. For example, if the child is not using any sound or speech, rather than communicating with them through words, try using gesture. The disabled child may use some of the following to communicate with others: crying, taking the adults hand to the object they desire, looking at the object they desire, reaching, using pictures and echolalia.

Echolalia is the repetition of other people's words and is a common feature of children with learning disabilities. Initially when the child uses echolalia it is likely that they are repeating words that they do not understand and are doing so with no communicative intent. However, echolalia is a good sign as it shows that the child's communication is developing - in time, the child will begin to use the repeated words and phrases to communicate something significant. For example, the child may memorise the words that were said to them when they were asked if they would like a drink, and use them later, in a different situation, to ask a question of their own.

Being successful in communication with a disabled child, does not only involve an understanding of how they communicate but also requires an understanding of why they communicate. In understanding the purpose of the child's communication you can help the child find more ways and more reasons to communicate.

There are two main different types of communication:

- i. **Pre-intentional Communication:** this is when the child says or does things without intending them to affect those around them. This type of communication can be used by the child to calm themselves, focus themselves or as a reaction to an upsetting/fun experience.
- ii. **Intentional Communication:** this is when the child says or does things with the purpose of sending a message to another person. This type of communication can be used to protest about what they are being asked to do and to make requests.

Intentional communication is easier for the child once they have learnt that their actions have an effect on other people - the move from pre-intentional communication to intentional communication is a big step for a disabled child.

The four different stages of communication

The stage of communication that the child has reached depends on three things:

- i. Their ability to interact with another person
- ii. How and why they communicate
- iii. Their understanding.

Stage one - the own agenda stage:

A child at this stage of communication will appear uninterested in the people around them and will tend to play alone. Their communication will be mainly pre-intentional.

Stage two - the requester stage:

At this stage the child has begun to realise that their actions have an affect on other people. They are likely to communicate to the adult about what they want and what they enjoy, by pulling them towards objects, areas or games.

Stage three - the early communicator stage:

At this stage the child's interactions will begin to increase in length and become more intentional. The child may also begin to echo some of the things that they hear to communicate their needs. Gradually the child will begin to point to things that they want to show the adult and begin to shift their gaze. This is a sign that child is beginning to engage in a two-way interaction.

Stage four - the partner stage:

When the child reaches this stage they have become a more effective communicator. The child will be using speech to talk and will be able to carry out a simple conversation. While the child may appear confident and capable when using communication in familiar environments (eg at home), they may struggle when they enter unfamiliar territory (eg at a new nursery or school). It is in this situation that they may use memorised phrases and can often appear to be ignoring their communication partner by speaking over them and ignoring the rules of turn taking.

Ways that adults can affect the communication of a disabled child

Take on the role of a helper and teacher:

When the child is unable to communicate their needs it is tempting to help them by constantly doing things for them. For example, fetching their shoes and tying their shoelaces. However, by doing this the opportunities for the child to show that they can do such things for themselves are reduced. When the child is at the Own Agenda Stage it is particularly difficult to decipher how much to do for the child. In this instance it is appropriate to ask the child if they need help, wait and then ask a second time before adding the help.

Instead of letting the child do their own thing, encourage them to do things with others:

It is tempting to believe that the child is merely showing their independence when they show no interest in interacting with the adult. However, it is important that the child does learn to interact and is not just left to their own devices. In this instance the key is to persevere with joining in with whatever activity the child is engaged in, whether this is playing with a piece of string or taking

toys in and out of the toy box. If the child shows anger and aggression when this is tried, still persevere. Anger is a type of interaction and is better than no interaction at all. Sometimes joining the child with his activity means just to sit next to him. For example when an autistic child stares at one point all the time, communication can be stimulated just by sitting next to him and stare together. As this interaction is continued with the child they may begin to realise in time that interaction with another person can be fun.

Slow down the pace and give the child a chance to communicate:

Caring for a child with a disability can be hard work and time consuming. There is often the temptation to rush the child when they are performing daily tasks such as eating breakfast and getting dressed. A child with disabilities will benefit from an extra few minutes extra time when engaged in these tasks to help them understand what is happening around them and to think about what they can say during these activities.

When playing with the child take on the role of a partner rather than a leader:

As the child becomes more capable at communicating, they need less direction - if they are given too many questions and suggestions it can become difficult for them to initiate their own conversations. It is important to follow the child's lead and respond to what they do, instead of taking the lead yourself.

Present the child with feedback:

It is important to reward the child when they attempt to understand and communicate. By doing this you can increase the likelihood that they will try and do it again. By using simple descriptive praise that comment on what the child has achieved, the child can make a connection between their own actions and your specific words.

Giving a disabled child a reason to communicate

If a disabled child has no difficulty getting what they want, they will have no reason to communicate and interact. Therefore, on many occasions the adult will need to engineer a situation in order to create a communicative opportunity for the child and encourage interaction.

Encouraging requests:

This can be achieved by placing the child's favourite toy/food/video in a place where the child can see it but is unable to reach it, for example, a high shelf. Alternatively, place the child's favourite object in a container, which the child finds difficult to open such as an old ice-cream tub or an old jam jar. This will encourage the child to ask for help and result in an interaction between adult and child.

Give the child a toy that is difficult to operate:

Wind up toys and games that need to be squeezed to make them work will be difficult for the child to operate alone but will also interest the child. Once the child has been given the toy/game, allow them some time to establish how to use it. When the child becomes frustrated at their inability to work the toy/game, the adult can step in and help them.

Give the child a toy that is "high interest":

Balloons and bubbles are high interest toys and can be easily adapted to involve two people. Simple games such as blowing up a balloon and then letting it go so that it flies up in the air may appeal to the child. Blowing up the balloon part way and waiting for a response from the child before blowing it up to its full capacity is also a clever way to enhance interaction between adult and child. A similar thing can be achieved with bubbles - blow a few bubbles towards the child, once their attention has been captured, close the container and wait for a response from them before you blow any more.

Give things to the child gradually:

If the child is given everything that he wants, he will have no reason to ask the adult for anything else. By staggering how much food/how many toys are given to the child they are provided with opportunities to interact by expressing their wants and needs. For example, if the child wants a biscuit, break it into small pieces, initially give them one piece and then gradually given them more once they have communicated a request for it.

Let the child decide when to end an activity:

Once the child is engaged in an activity with the adult, carry on with that activity until the child indicates that they have had enough. Look out for facial grimaces or the child pushing away the activity. This way, the child is forced to communicate that they are ready to finish the activity. If the child does not use language to indicate they have finished, accompany their form of communication with words such as had enough and stop to encourage their language development.

Increasing interaction by following the child's lead

Following the child's lead rather than directing them will enable them to learn to communicate while they do things with another person, hence increasing their interaction. The child that leads is more likely to pay attention to the activity, more likely to focus on the same thing as the adult and will learn how to make choices for themselves.

When following the child's lead it is beneficial to be in a position where the adult is face-to-face with the child, this way the adult can easily observe what it is that the child is interested in. It will also help the child to make eye contact - something that can often be difficult for children with autism or learning disabilities. Being level with the child will also ensure that they are in a position to see the variety of facial expressions that are used in communication. A disabled child may often fail to pick up on these non-verbal communicative behaviours during conversation; therefore, it is important to draw attention to them where possible. It is hoped that the child will eventually become used to the adult playing with them at their level and begin to anticipate their presence, fetching them if they are not there.

Imitating the child's actions and words will help the child become involved in two-way interactions. If the child bangs the spoon on the table, and the adult does the same, it is likely that the child will pay attention to the adult. This idea can also be used with sounds that the child makes or with the child's sensory behaviours, for example, hand flapping and spinning. Once the child has established that the adult is imitating her actions, they may begin to imitate back. This creates the opportunity for the adult to add something new to the exchange for the child to duplicate.

When a disabled child is disinterested in playing with any of the toys presented, or prefers to line toys up rather than play with them, there are still communication and interaction opportunities available. For example, if the child is lining up their cars in a row, the adult can join in the activity by handing the child the cars one by one. This way, the adult plays a part in the game and the child has to include them in what they are doing. If the child is only interested in throwing the toys on the floor, the adult could use a basket to collect them before giving them back to them, thus establishing a pattern of interaction and communication with the child.

Ways that adults can help a disabled child understand what is said to them

A disabled child will find processing information a difficult thing to do. This is because they may find it difficult to understand the world around them. Even when the child does understand a situation, they may not understand the words that go with that situation. Sometimes it is easy to assume that the child understands what is being said to them because they appear to follow

instructions. However, the likelihood is that the child will know what to do when instructions are given in certain contexts because they have done it numerous times previously.

There are several ways in which to enhance a child's comprehension of what people are saying to them.

Say less and say it slowly:

The adult can limit the amount of words they use to communicate with the child but still communicate the relevant information. Use key words that are specific to the context of the situation, repeat and stress them and use gesture, such as pointing, to accompany them. Sussman (1999) uses the following rhyme as a reminder of how an adult make it easier for a disabled child to understand them:

"Say **less** and **stress**, go **slow** and **show**!"

If the child has only recently begun to use speech as a means of communication, the adult should use single words to communicate with them. For example, labelling favourite toys and food. When using this method of communication it is important to label things when they are immediately given to the child. If the child's attention has shifted onto the something else, the word will lose its meaning.

Pausing in between spoken words and phrases can also help a disabled child understand what is said to them. The adult should use pauses to give the child time to process what has been said to them and to give them an opportunity to think of a response.

Using gestures to accompany language can also encourage the child to understand what is being said to them. For example, when offering the child a drink the adult should gesture the action of drinking by pretending to hold a glass in one hand and bringing it their mouth as if they were taking a sip. A similar thing can be used for eating. Over exaggerated facial expressions can also be used along with shaking the head for "yes" and "no" and a waving of the had for "hello" and "goodbye". When talking to the child about people, for example "grandma is staying", it helps to present the child with a photo or drawing of who is being spoken about.

Other visual methods that can be used to increase understanding include picture timetables, line drawings, cue cards and object/picture schedules.

What aid and adaptations are available for helping me communicate with my child?

Using Augmentative and Alternative Communication (AAC) supports

AAC describes any form of language other than speech that assists a child in social-communicative interactions. In many Countries there is a large range of AAC devices available for children who have no speech, and these children themselves are very diverse. Some of these are only now becoming available in Kyrgystan. Therefore, it is essential that a team of appropriate individuals evaluate different AAC options with the parents of a disabled child before a decision about their use is made. This team might include a social worker, defectologist and psychologist.

The use of AAC devices for children with disabilities can be particularly helpful. Those children who have no spoken language often resort to challenging behaviours to meet their needs and feelings. The use of an AAC device can give them a primary means of social communicative interactions with others. If it is decided that an AAC device is appropriate for the child it is the responsibility of those around them to model the system.

In Kyrgystan some professionals feel that children should only be encouraged to use verbal communication and that this will only develop if other forms of communication are restricted. However, many countries have now developed what is known as a Total Communication approach. Total Communication is the use of combined speech and sign so that the same language structure is modelled for the child in two modalities. The use of total communication helps to highlight key word meanings and help language comprehension. This use of communication can be especially helpful for children with learning disabilities such as Autism and Downs Syndrome and Deaf and Hearing impaired young people although other disabled children can often benefit.

The most important thing is that your child's level of learning and understanding develops, and that you and others can build a positive relationship with your child. This can not happen without you developing communication methods at an early stage with your child and if verbal communication is delayed other forms of communication should be sought.

Different types of AAC devices that are suitable for disabled children include:

- Picture Exchange Communication System (PECS, Frost and Bondy, 1994)*
- Sign Language
- Interactive Communication Boards
- Communication Cue Cards
- Conversation Books
- Voice Output Communication Aids.

Sign language:

There are several difference sign language systems, for example, Russian Sign Language, Kazakh Sign Language, Simplified sign Makaton *Nazgul:does kyrgystan has an own signe language????*. When using sign language with a disabled child, it can be beneficial to use a total communication approach. Contact the deaf and blind society *are there such organizations here in Kyrgystan????*for more information about free and paid courses and literature for parents.*Mention ARDI office and our information recourse centres in Talas, Social Work society??????*

Interactive communication boards:

Interactive Communication Boards contain visual symbols in a grid form organised by topic. They can be created in different sizes and formats depending on the activity and environment that they are needed for. They can be both portable and stationary - one board is designed to stay in one location. The selection and organisation of the symbols that are used need to be motivating and chosen to enhance functional communication for the child. These can be created by specialists and families together. Bliss symbol is one example of communication board. However, communication boards can also be made with photographs, pictures and hand drawn symbols – create whatever your child understands best.

Cue cards:

Cue cards are primarily used with verbal children. They are used to remind the child what to say and to provide them with an alternative means to communication. They can contain one or more messages in pictorial or written form and can replace verbal prompts. They are therefore, particularly useful for children who are reliant on verbal prompts. Cue cards can work well in situations where the child needs to express a message in a stressful situation.

Conversation books:

A conversation book can be pictorial or consist of a written summary of conversation topics used for increasing conversational abilities. The conversational topics are organised in a small book, wallet or something similar and are used as a focus of conversation with an adult. It is important that the book is age appropriate and the topics chosen, meaningful to the child. This can often be achieved best using photographs - especially for the younger child. Conversation books work by organising the conversation for the child. They provide a concrete, visual means to share and maintain topics.

Voice output communication aid:

Speech output devices give non-verbal children a "voice". A team of relevant professionals should determine the most appropriate technology option. Once this has been established the team then need to decide on an appropriate vocabulary selection, the layout of the device, the size of the symbols and the principal situations to encourage the child to use the device. There are a wide range of devices available including simpler ones for people who do not understand visual symbols. In order to use these devices, the child will need an understanding of cause and effect. These can be particularly effective for children with cerebral palsy or other physical impairments that impact on speech. These devices are very expensive and not available at this present time for free in Kyrgyzstan. (*Nazgul, is this correct????*)

The combined use of AAC, social supports, organisational supports and visually cued instruction can enhance the social communicative interactions for disabled children.

How can I improve the physical, emotional, intellectual and social development of my child?

Specialists as physio-therapists and massage can help greatly in supporting you to improve the physical development of your child. Other specialists such as psychologists, defectologists and social workers can help with intellectual and social development. However, still many families, especially those in rural areas may have no access or limited access to services. The following activities suggested below are things that you can do to help improve your baby's / child's overall

development. Most parents think that you need to buy expensive toys specially developed in order to improve development. This is not true. You can do many activities that have the same or have an even better impact on your child's development, as they are more personal for you and your child. The most important thing to remember is that your child needs stimulation if they are to develop. They need to enjoy the activities if they are to learn and remain interested in completing activities with you. Use these activities to have fun and learn how to communicate with your child. You will notice their strengths and development and build a positive relationship with your child the more time you are able to spend doing these things. Children who are left to lie down all day without access to play and conversation will deteriorate psychologically and physically. Sometimes it is easy to "forget" about a non verbal child or a physically disabled child but your child has the right to be valued, loved and stimulated and these exercises are one way that you can do this.

For babies and small children

- Blow at all parts of your baby's body, rub, pat and prod him. Roll him around.
- Place the baby onto a scratchy woollen blanket or crackly paper so that the nerves of the body experience something quite different. The noise of the paper will be an incentive for him to move. Sounds are the baby's reward.
- Forget about the baby's comfort **now and then**. Put him too near the foot-end of the cot. He may want to push against it. Place the baby on his tummy and hold some bright, noisy object in front of his eyes, but above the head. This will encourage him to lift the head and exercise the neck muscles.
- Whistle and sing if it makes the baby stretch or arch the back. Use odd sounds, which suddenly lapse into peaceful silence. Do not be afraid to be child-like with your baby. It is surprising how aahs and oohs (*Nazgul, do people also do this in Kyrgyzstan???*) can provoke wriggles and happy twisting which no serious talk can ever achieve.
- Do not place bells only near the hands but put them also on and near the feet. This will make the baby kick more frequently and more purposefully. If the bells are placed on the sides, he will even learn to use alternate limbs.
- Carry the baby around in a baby sling. In this way she gets rocked, lowered, lifted and turned without much effort on your part. This stimulates the sense of balance while she feels loved and a part of everything you do.
- Tease the baby into turning, stretching or bending movement by holding a desired object at a slight distance. It may be good for an inactive baby to learn that effort has its reward.
- If the baby does not attempt to crawl, give her the joy of a bath in which you lie her down on her tummy over a large rolled up towel. This comfortable bulge should support the chest and abdomen while leaving the limbs to dangle freely in the water. When splashing in this position, the baby may come very close to the mechanics of crawling.
- It is helpful to do things together with the baby, to get down with her at times. For the baby the task at hand is gigantic. Why must we then make it harder still by standing over her like a giant? If the legs are still lifeless or weak and the knees still unused, you can sit

opposite your baby on the floor, with the soles of your feet touching her feet, and push against each other. You can be the wall on which the baby gradually raises herself from crawling to a standing position. You can make a ramp with your legs on which she can learn to climb.

- Last but not least, make your child itch with curiosity. Do something secretive nearby, or clatter about unseen so that the child will want to overcome the physical stumbling block and get up!

For older children

Motive Functions:

- * Help a child walk by supporting his hands (Don't support under the arms!).
- * Let him walk himself between two rails.
- * A wheeled truck /laddered back chair or walking aid that your child can push will help stability.
- * Arrange different size boxes that he must climb.
- * Place toys that encourage him to bend and twist.
- * Encourage him to walk barefoot on different textured surfaces.

Research shows that before being able to walk a child must first be able to roll over and sit alone.

Fine Hand movements:

- * Give a child a box and different types of objects. Ask him first to put things in the box and then take them out again.
- * Make some small cloth bags and place inside peas, grain etc. Let him guess what is inside. Then let him open the bag and take a look. This helps to develop knowledge and fine movements.
- * Give him some old clothes that have big buttons. Ask him to button and unbutton it.
- * Ask him to build a tower/ pyramid out of small boxes. Or make other shapes/ items out of plastic bottles, containers etc.
- * Thread beads onto a thread to make jewellery and attractive mobiles for your home.

Intellectual Development:

- * To increase knowledge and vocabulary

Cut pictures out of old magazines and paste them on a box. Ask a child to show and repeat what is on the picture. ("Show me a car" etc.)

Read a picture book together – ask questions about the book and what is in the pictures.

- * Colours

Use a toy pyramid. Ask to put rings of a definite colour. Ask what colour is a certain ring. (If you don't have this kind of toy then just use a collection of objects of different colours and do the same exercise)

When you draw together name a colour of the pencil you use

When you walk show and name colours of objects you see.

* Memory and attention

Draw various simple geometric objects (circle, square, triangle, star etc.) Cut them and colour them in different colours. Put them in a certain order, ask a child to remember how they are placed. Then mix them and ask a child to replace them as before (or if they have mobility problems get them to tell you how to replace them). Start with two objects and build on this gradually.

Do the same activity with the figures of known animals, photo's of family members, other objects.

Cut a picture or postcard into four parts and ask a child to put it together.

* Vocabulary

Speak to a child wherever you are in the house.

Read aloud simple stories and ask the child to repeat what you have said or what is in the pictures of books.

Make up your own stories and encourage your child to do the same.

Show and name everything that is around.

Children often learn quicker from other children than from adults and this is a more inclusive way of helping your child. Use every opportunity for your child to meet and play with other children of different stages of development.

Part 3 include or not, ask Meder!!!!!!!!!!!!!!!!!!!!

Legislation and Systems International Legislation

We have included a section on International Legislation because all Kyrgyz legislation needs to comply with international legislation. It is very difficult and time consuming to take any legal cases against the Government based on International Human Rights Instruments. However it is important that you are aware of international binding agreements and legislation so that you can highlight what Nationally and Locally Government bodies should be working towards. We have tried to make the language in this section as simple as possible in order that it is clear and understandable.

What are Human Rights?

Introduction

Human rights govern the relation between government and the individual. They are regarding the individual, who shall be able to exercise them either alone or together with others. So a person with a disability and their family should all be protected within this, although the first right of protection is with the disabled person. These rights address government, which means that every right for the individual is also an obligation on the part of government.

The following points should be made clear straight away:

- Human rights are universal. In other words, a violation of a human right is a violation no matter where in the world it is committed. Therefore a state can never excuse a violation of human rights by pleading tradition, religion, culture or suchlike.
- Human rights apply to all human beings without distinction – that is to say, irrespective of race, colour, gender, language, religion, political or other convictions, national or social origin, property, birth or status generally. No one may be discriminated against or impeded from the enjoyment of their rights
- The state (for Kyrgyzstan this is the Kyrgyz Government) has a responsibility for the realisation of rights in society. This balance between rights and obligations is fundamental to human rights.

The Universal Declaration of Human Rights, adopted by the United Nations on 10th December 1948, is the first international document acknowledging universal human equality of dignity and rights. Since then, its 30 articles have been elaborated in successive declarations and conventions adopted, for example, by the Council of Europe, the UN General Assembly, other UN agencies and other bodies.

First- and Second-generation rights

Although civil and political rights must nowadays be considered inseparable from economic, social and cultural rights, certain distinctions still have to be made concerning rules of compliance.

Where “first-generation rights” are concerned – meaning civil and political rights – states are in principle obliged to observe them immediately on ratifying the text, whereas second-generation – economic, social and cultural – rights can be introduced by stages, as article 2 of the convention makes clear:

1. Each State Party to the present Covenant undertakes to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realisation of the rights recognised in the present Covenant by all appropriate means, including particularly the adoption of legislative measures.

The word “progressively” merits special attention. Contrast this with article 2; point 2 of the International Covenant on Civil and Political Rights:

2. Where not already provided for by existing legislative or other measures, each State Party to the present Covenant undertakes to take the necessary steps, in accordance with its constitutional processes and with the provisions of the present Covenant, to adopt such laws or other measures as may be necessary to give effect to the rights recognised in the present Covenant.

Another distinction is that all rights, which do not cost the state anything, must be provided for, but this in a way is an overstatement. The state cannot always be excused from giving effect to rights, even when there is expenditure involved. For one thing, “progressive” development has to be taken into consideration, and secondly, an analysis has to be made to see, for example, whether money for the realisation of a right is really unavailable. If, for example, any amount of manpower and funding are devoted to some other field, the state may find itself under an obligation to distribute resources better.

Violations of human rights

The definition of an infringement of international law has for a long time been a tricky question. On 22nd-26th January 1997 about thirty international law experts gathered in Maastricht (The Netherlands) to discuss and investigate the meaning of violation of economic, social and cultural rights. The Maastricht Guidelines adopted on that occasion have also been recognised by the UN. The document describing how General Comments are to be written lays down among other things that breaches of the convention are to be defined with reference to the Maastricht Guidelines. The Maastricht document also lays down appropriate accountability and appropriate methods for overcoming violations of different kinds.

The Guidelines state that economic, civil, social, political and cultural rights imply three different types of obligations on the part of states, namely to respect, protect and fulfil the rights to which the treaty refers. Failure to perform any one of these three obligations constitutes a violation of such rights.

All of the following quotations come from the UN Universal Declaration of Human Rights, which is the foundation of the human rights that other instruments – both conventions and declarations – take as their starting point. The Declaration, moreover, is, as its title implies, universal.

The right to work, article 23 (2nd Generation Right)

“1. Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment.

2. Everyone, without any discrimination, has the right to equal pay for equal work.

3. Everyone who works has the right to just and favourable remuneration ensuring for himself and his family an existence worthy of human dignity, and supplemented, if necessary, by other means of social protection.”

The right of social security, article 22 (2nd Generation Right)

“Everyone, as a member of society, has the right to social security and is entitled to realisation, through national effort and international co-operation and in accordance with the organisation and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality.”

The right to education, article 26 (2nd Generation Right)

“1. Every one has the right to education. Education shall be free, at least in the elementary and fundamental stages. Elementary education shall be compulsory. Technical and professional education shall be made generally available and higher education shall be equally accessible to all on the basis of merit.

2. Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms. It shall promote understanding, tolerance and friendship among all nations, racial or religious groups, and shall further the activities of the United Nations for the maintenance of peace.

3. Parents have a prior right to choose the kind of education that shall be given to their children.”

In 1994 the Spanish government, acting in close collaboration with UNESCO, arranged a conference on “Special Needs Education: Access and Quality”, otherwise known as the Salamanca Conference, the aim of which was to address the deficiencies besetting special instruction for children with disabilities. The Statement issued by the conference declares that all children, regardless of disability, should attend “regular” school unless there are strong reasons to the contrary.

Special resources of both staff and funding shall be set aside in order for children with disabilities to receive the support they need in order to succeed educationally. The conference also drew up a “Framework for Action on Special Needs Education”; i.e. policies and guidelines on ways in which schools can improve the situation and make education possible for children with disabilities.

The right to physical and mental health, article 25 (2nd Generation Right)

1. Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

2. Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.”

The right to marry and form a family, article 16 (1st Generation Right)

“1. Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family. They are entitled to equal rights as to marriage, during marriage and at its dissolution.

2. Marriage shall be entered into only with the free and full consent of the intending spouses.”

The right to freedom of association, article 20

“1. Everyone has the right to freedom of peaceful assembly and association.

2. No one may be compelled to belong to an association.”

The right to freedom of opinion and expression, article 19

“Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.”

The right to participate in elections and to be elected to office, article 21 (1st Generation Right)

“1. Everyone has the right to take part in the government of his country, directly or through freely chosen representatives.

2. Everyone has the right to equal access to public service in his country.

3. The will of the people shall be the basis of the authority of government; this will shall be expressed in periodic and genuine elections which shall be by universal and equal suffrage and shall be held by secret vote or by equivalent free voting procedures.”

UNCRC 1989

The United Nations Convention on the Rights of the Child (UNCRC) is a globally binding instrument of great importance. This convention makes special mention of children with disabilities. A powerful instrument, it has been ratified by all member countries of the United Nations except for the United States and Somalia, and also by five non-member states, making 191 signatories altogether. Kyrgyzstan ratified the Convention in 1995 ***This is correct????***. **The most important thing about the UNCRC 1989 is that it states that disabled children should have the same rights as every child and should not be given unequal treatment. It also states that Governments need to provide additional services for disabled children to keep them safe, independent and included.**

Article 23 provides:

States Parties recognise that a mentally or physically disabled child should enjoy a full and decent life, in conditions that ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

Article 2 provides:

States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.

There are many other documents regarding the International Human Rights of disabled children and adults. We will not go into detail here about what these are as it is maybe more useful to focus on how these have been integrated into Kyrgyz Legislation and how on a National level Disabled People can challenge service providers based on the Law of the Republic of Kyrgyzstan.

Kyrgyzstan Legislation

There has been a large number of legislations that have been developed in the Republic of Kyrgyzstan that impact on disabled people and their families. The most notable and important of these legislations are:

ask Every Child Lawyer!!

The Law of the Republic of Kyrgyzstan for the Social Protection of Disabled People. Date

Law on Social, Medical Pedagogical and Rehabilitation Services for Children with Mental and Physical Disabilities

Part 4 How does the system work, which professional is involved

How Do I Access My Rights?

Understanding your rights under legislation and accessing them can be two different things. Often parents and disabled people find a huge gap between the legislation and what they experience in practice. This is true in many countries, although in Kyrgyzstan one of the difficult things to decide is what to do about it.

There are two main things that you need to do in order to access your Rights under Legislation in Kyrgyzstan these are:

1. Secure registered Invalid Status for your child at the Medical Social Expert Disability Commission.
2. Secure recommendations regarding the rehabilitation of your child from a PMPK Assessment.

Registered Invalid Status

By achieving registration for your child you will then become entitled to benefits, adaptations and aid for your child. Ask a social worker to help you with this process.

PMPK Assessments

By going through the process of a PMPK assessment you will achieve an Individual Rehabilitation Plan for your child that will provide access to medical, rehabilitation, social and educational services for your child.

These two processes are not interlinked. Some families may have gone through a PMPK assessment without having registered their child. Other families may be receiving financial support without having access to services. Your child is entitled to both types of services and the information in this chapter should support you in receiving these entitlements.

Registration of your child as Disabled.

It is important to have your child registered as a disabled child for a number of reasons:

1. You do not have the right to receive benefits, free prescriptions or tax benefits if your child is not registered as having a disability.
2. Services in your area will remain under funded if the numbers of disabled children remain unknown.
3. It enables local Akimats to predict what future needs the area has in terms of early screening, improving medical and social services, increasing medical and social services, housing, schools etc.
4. It helps identify any causal trends of disability – for example if many children in one area are born with a disability causes such as bad ecology, or poor water supply may be more easily identified and preventative services can be developed.

However, it is not always easy to get your child registered as disabled and many people do not understand the system.

How to get your child registered: **(Nazgul, please check if I'm right!!!!)**

1. In order for your child to be registered as disabled there first needs to be an assessment. This can be done at your local polyclinic where a team of specialists including a neuropathologist will complete a recommendation form to the city or regional Medical Social Expert Commission.
2. You will then be told to attend the Medical Social Expert Commission, where a further assessment will be completed and the disability commission will make a decision to register your child yes or no as disabled.
3. If the Disability Commission refuse to register your child as disabled you have the Right to find out why. You may need some help to challenge this decision. You can attend the Medical Social Expert Commission again but it is important that you get support from other medical and social professionals so that you can provide more evidence that shows that your child is disabled in order that they may change their initial decision. Ask a Social Worker to support you.
4. One of the things that families find very difficult is that they need to re-register their child every year and this requires the same process of assessment every time. This can be useful if there has been an improvement or deterioration in the condition of the child, however generally families find this a time and energy consuming process.

Entitlements from Registration Nazgul, please check this chapter!

You are entitled to the following things once your child has been registered as disabled:

1. A disability benefit. This is given on a monthly basis and varies depending in which region you live. All children with invalid status will get the same amount in your region regardless of level or type of disability. **(Nazgul. Or am I wrong and depends it on the category????)**
2. Tax relief benefit. One of the parents who is working is entitled to not pay taxes if they have a disabled child. **(Nazgul, please check if I understood right!)**
3. Free prescriptions. All families who have a disabled child are entitled to free prescriptions for that child. Unfortunately that does not include all drugs, just those named on the list as free. **(Nazgul, can we get a list from the first hospital which medications are for free?)** These drugs maybe the cheapest versions, or less effective than another drug but they are free. Sometimes pharmacies may try to say that they don't have those drugs and try to sell you an expensive equivalent. Try not to pay – it is your Right to have free prescriptions and it may be worth searching for a good pharmacy that protects this Right.
4. Aids and adaptations. Hearing Aids, Wheelchairs and prostheses are available free of charge if you have been medical assessed as needing them. **(Again, am I correct?)** You can get this assessment from a specialist doctor (Orthopaedic doctor, Paediatrician etc), PMPK assessment or even the Medical Expert Social Commission can assess you as needing these aids. Then you will need this doctor to fill in a recommendation form for the distributors before you can receive your aid. Different aid and adaptations are distributed

differently, some are distributed from the Akimat others from NGO's. Please read the rules carefully. For example you may be entitled to a free hearing aid only once every 3 years. If your aid is lost or breaks in that time scale then you may not be entitled to another free one. Always take great care of your equipment as replacements are difficult to obtain without paying.

5. Free Access to Leisure and Recreation activities.

6. **Disabled people can park their car for free! (Nazgul, can you include a list with nice places for disabled people to park their limousine?)**

PMPK SERVICES – What are they?

Nazgul, please check this chapter and correct, add, etc.)

The reason that PMPK services have been developed is to provide disabled children with an assessment that looks at their medical, social and educational needs and how these are all interlinked.

PMPK assessment centre's are found on both a city level and an oblast level. There is also one PMPK that is a Republic Centre and this isin Bishkek **Nazgul, correct? Do we have address?).**

In order to receive rehabilitation and educational services for your child it is very important that you attend a PMPK assessment. These are always free and you should not be asked to pay for an assessment. Sometimes these assessments take place over a period of a few days and therefore you may need to live close by to the centre where the assessment takes place, for the period of assessment.

What Will Happen?

Your child will be examined and assessed by a number of specialists these may include:

- Psychologist
- Paediatrician
- Defectologist
- Speech Therapist
- Physiotherapist

You may also be asked to talk about your social situation with a social worker. A social worker will complete an initial assessment (social passport) and from this may be able to help and advise you on your entitlements and develop social support services for your family.

Individual Rehabilitation Plan (Nazgul, this was Kazakh name/system, also Kyrgyz?)

From this initial PMPK assessment you will be provided with a set of recommendations for services that will meet the child and families needs. These will be developed into an Individual Rehabilitation Plan. This individual rehabilitation plan will set out the aims of the services, how often you will receive them and which specialists will deliver these from which organisations.

How to access PMPK?

1. It is very important to first go to the PMPK in your area. This may be a city PMPK or oblast PMPK. This is because they are aware of local services and will be able to develop an individual rehabilitation plan for services in that area.
2. If you are not happy with the results of the PMPK assessment in your area you can ask for a re-assessment at that PMPK, or you could attend the city or republic PMPK for a second assessment.
3. Getting a PMPK assessment can be very stressful for parents. Ensure that you are well prepared and that your child is well prepared and knows what to expect. Take someone along with you to support you and enough toys and refreshments for your child during the day. Often city and oblast PMPK's can be very busy and you may need to wait around to see the correct specialist. Try calling your PMPK in advance to make an appointment or gain more information about what you can expect when you go for your assessment. You can also ask a social worker for advice.
4. Disabled children need to attend PMPK assessments every year to ensure that their individual rehabilitation plans are updated and meet their developing needs. Establishing good relationships with specialists in the PMPK is important in order that your disabled child's needs can be continually assessed, monitored and addressed.
5. If you don't agree with the recommendations made by PMPK – talk to the specialists about it. It may be that your child has had an “untypical day”. Often children react differently in a new environment and your child may have chosen not to engage in the assessment activities. Provide a full picture of how your child is usually - with examples. Also get involved in the assessment with the specialist as the child will probably react more naturally if you are also involved.

I want a diagnosis or to understand my diagnosis!

Having a diagnosis is often very important for families. It is very important on a number of levels:

- Emotionally and psychologically it can be very important for families to know exactly what impairment their child has. It is difficult to accept and understand a disability if you don't know what impairment has caused the disability.
- Securing support and services. Having a diagnosis may help you secure additional services for your child or help you challenge decisions that have been made about your child.
- Finding out more information. Once families have a diagnosis they often start to search for information about that impairment through leaflets, books and seeking out other families with the same diagnosis.

However, getting a diagnosis is not always easy or possible. There are a number of barriers that families might face.

Specialists not knowing the Diagnosis

There are some disabilities that have no known specific diagnosis. For example a child may be diagnosed as having delay or a learning disability, but this may not leave the family satisfied about what is causing the delay or disability. It may be that families feel that the specialist is not qualified or competent enough to give a diagnosis and may want to go for a second opinion. This is always an option but before you do this it is important to remember that in all countries of the world, even the most medically advanced countries it is often difficult to identify one diagnosis for a child who presents a complex condition. This is hard for families to accept and they may go on a

search to find a diagnosis for their child. The reason many of them do this is because they feel if they could find a diagnosis they could also find a cure. Remember that although many disabilities can be improved, the majority can not be cured. Balance the rights of your child to not have to undergo countless medical tests that may have little results with your right for the best medical information about the condition of your child. A general diagnosis such as physical disability or psychological disability will still give you the same access to services and financial support under Kyrgyz Legislation.

Specialists knowing the Diagnosis but not telling the Family

It may be that the specialist knows the diagnosis but chooses not to share it with the family. This may be because the child is still at an early stage in their development and the specialist may feel that the diagnosis could change or develop. However, parents do have the right to know about medical diagnosis and decisions made about the diagnosis. It may be useful for you to say that you understand that the condition and diagnosis may change but express that it is important for you to know at this early stage what the specialist thinks. Approach the specialist as a partner in trying to together understand your child's condition.

Families not understanding the Diagnosis

Sometimes a diagnosis is provided but families do not understand the diagnosis. You have the right to ask for the diagnosis to be explained by the specialists who gave this diagnosis and ask them about how that may impact on the child and the family. It is sometimes helpful to have someone with you to ask these questions, you may invite a friend, another parent who has a disabled child who understands the system, or a social worker to support you.

Although it is often best to get the information about the diagnosis from the specialist completing the assessment, there is a wealth of information available regarding different disabilities. Contact NGO's and Governmental organisations to see what information or support groups they have available. Always check out the validity of this information from lots of sources. Even good and medically proven procedures may not actually benefit your particular child if their condition is slightly too severe or different. Make a decision based on all the facts and what your child wants/needs.

Diagnosis based on Medical Assessment rather than Need

One of the main difficulties regarding the diagnostic system in Kyrgyzstan is that it is based on medical assessment and not the needs of the family. Consequently services are distributed based on purely medical factors, although financial and social factors also impact a great deal on the family's ability to cope with the challenges that they face when they have a disabled child. It is therefore important that you present the specialists with as much information as possible so that they may take these factors into account when making recommendations.

Advice for Parents – Approaching a diagnostic assessment

Before diagnosis/ assessment

1. Make sure you are clear about your entitlements before you start the process and take with you appropriate legislative information.
2. Remember you know your child better than anyone. In many ways you are the expert on your child's ability's and needs. Make sure that you provide the specialists with full

information about your child's abilities even if they don't ask or seem disinterested. It maybe better to write these down so you don't forget.

3. If you don't understand what a specialist is saying then tell them. Ask as many questions as necessary until you are clear about what they are saying and the implications of this.
4. Take someone with you to support you. This may be a family member or a specialist who is supporting you and understands the system. Often organisations of disabled people may be able to help you and advocate alongside you.
5. Take notes throughout the consultation. Make sure these notes are accurate, where possible quoting what the specialist says. Write the name of the specialist and date of the consultation. This ensures that you don't forget important information that the specialist tells you and also helps you to understand the information provided. Also when you see so many specialists, details and names may get mixed up. This gives you a clear record of your progress and helps keep information clear.

After Diagnosis

6. If you don't agree or are unhappy with your child's diagnosis don't just accept the diagnosis that you are given if you feel it is not right. Question doctors ask them how they came to their decision – provide them with information you feel they may have overlooked. If necessary ask for a second opinion.
7. Find out as much information about your child's diagnosis as you can – not just local information but International information. Look for positive achievements of disabled people and strive for the best outcomes for your child. Also look for innovative ways of working with your child. However, looking for “cures” can be time consuming, painful and expensive. Often it is better to look for positive ways that your child can learn and achieve and secure the support so that they can do this.
8. Register your child as disabled as soon as possible, as you only begin to receive benefits once your child is registered. You may be told that it is too early to register your child but it is possible to register your child before the age of 5. **Nazgul, is this correct? Is there such thing as a limitation according to age in Kyrgyzstan?)**
9. Don't give up – even though the fight is very hard and it is difficult to get results and your entitlements. But remember they are your entitlements so don't be put off when people say no.
10. If you are not happy with the level of services you receive then write letters stating your concerns and make sure you send them to the right people in order to get your voice heard. Don't just accept poor quality services or low level services.
11. Remember society has a very negative attitude towards disabled people – but there are many things about disabled people that are positive. Speak to parents of disabled people and disabled people themselves to gain support and share experiences. Ask disability NGO's to help you organise this.
12. Develop parents groups where you can meet together regularly for support – share information and advocate for your children's needs. It's always easier to strive for things as a group rather than as an individual.

Don't forget that your disabled child also has RIGHTS. Don't forget to talk to them throughout the process, even young children and severely disabled children. Explain to them the process, ask for their opinions. Balance the stress the treatment may cause with the results likely to be achieved. Parents can often do what they think is best for the child without asking the child's opinion. Remember that the child has Rights to also make decisions about what should happen to them – it is their life and their body after all. Make sure that specialists also ask their permission and involve them in decision making.

**Professionals working with Disabled People and what they do?
(Nazgul, I wrote this chapter in Kazakhstan. Is it useful for Kyrgyzstan?)**

Family Doctor- This is the local doctor who advises on a wide range of health concerns. Your GP can put you in touch with other medical services and may also be able to provide information that will help you apply for welfare benefits or other kinds of assistance.

Audiologists - work with people who have hearing difficulties and advise on hearing aids.

Defectologists – develop special educational programmes to prepare children for school and assess educational development.

School Psychologists - visit schools to assess children and advise on their learning and behaviour.

Genetic Counsellor Ask your GP, hospital doctor or family welfare centre to refer you.

Health Visitors - are nurses with extra training in advising parents of children under five years. They can be contacted via the GP.

Neurologists - are doctors specialising in the brain and nervous system.

Occupational Therapists – assess and evaluate condition and function through selected activities in order to enable people to function as effectively as possible in daily life. Can also supply and recommend specific equipment. Can be contacted via the GP.

Orthoptists – work with people who have visual problems and abnormal eye movements.

Paediatricians - are doctors specialising in the care of children.

Physiotherapists - specialise in assisting people with movement problems, using techniques such as exercise, manipulation, heat and massage to develop efficient patterns of movement. When working with a child with cerebral palsy they can also advise carers on ways of carrying, holding and positioning the child.

Psychologists – support the child and wider family to cope with stress and psychological problems resulting from an impairment, or discrimination that family's experience.

Social Worker - a social worker can advise on practical and financial problems, or tell you how to access local services. A social worker supports a family to be included in their communities and deals with social issues.

Speech and Language Therapist - these therapists can assess and support those with communication difficulties. If appropriate they may recommend communication aids or languages using signs or symbols. They also support those with eating, drinking and feeding difficulties.

Rehabilitation Centre's and Correctional Cabinets

Rehabilitation Centre's and Correctional Cabinets. They consist of professionals: psychologists, speech and language therapists, doctors etc., who can provide valuable information and assistance.

AKIMAT????

This is the government department, which is in charge of the payment of benefits to people with disabilities their families and carers.

Self help groups????

How Professionals should work with families?

As a parent or as a disabled person you will come into contact with many professionals. Most of these professionals will be in the medical profession and will probably view you in a traditional medical approach – as a problem that needs fixing. However, each family is individual – it has individual strengths and weaknesses and different needs for support. It is important that professionals see the human needs of families as well as the medical needs. The following advice is to support you to work well with the professionals you meet:

Find out what role the professional will take. Each professional has a different role and it is important that you know what you can and can't expect of them.

Be open and honest with the professional. They can help you only if you are honest about your difficulties and needs.

Build a relationship based on partnership. Often parents and disabled people expect professionals to have all the answers. They may demand answers and cures. It is much more useful to enter into a partnership with professionals and seek together answers that would work for the disabled person and their carers.

Don't be intimidated by jargon or the professional nature of the worker. If you don't understand something you have the right to ask. There should not be secrets held back from families. We know that professionals are busy but they should always have time for parents and disabled people's fears and questions. Don't be afraid to ask.

Learn from the specialist. The specialist should be able to provide support and advice about what you can do at home with a disabled child. This will enable you to provide better care for your child and the specialist will feel that you value their input.

Don't be afraid to tell a specialist that you disagree or that you are unhappy. The disabled child and their family know the most about how things are happening on a day to day basis and professionals need to listen and take action about what you need.

Part 4 Attachments

All leaflets we have

Play

Play is very important for all children, particularly so for those with some disability. Through play all children learn about themselves, their environment, and the relationship between the two. Play should stretch, challenge, stimulate and give pleasure to the child. To achieve this aim activities offered must be at the correct level for each child. A rattle is appropriate for a baby under a year old, but not for a child of 3 years. Pencils for drawing are appropriate for a child of 3, but not for a baby who would want to put them in his mouth.

Unfortunately many people seem to think that children with disabilities do not need to play. In fact they need to play more than normal children. By playing children discover first about themselves and later about the world around them. The first stage of play is to reach forwards to grasp objects which are then take to the mouth. Do you know why babies do this? It is because there is a greater concentration of nerve endings on the lips and the front of the mouth than anywhere else in the body. The next greatest concentration is on the finger tips. A baby needs to confirm what he sees and feels by checking with his mouth.

Handling forms an important part of play. Infants enjoy being cuddled, rocked in their parents' arms and sung to. From around 6 months old babies enjoy more active play such as being swung and held up in the air, and then as they grow older they enjoy being tossed and swung more vigorously. These forms of play are often performed by fathers or male members of the family, but may not be practised if the child has a disability. Some parents treat any child as if he might break, and this is more common with disabled babies and children. A very stiff or floppy child needs holding carefully and to be warned first before being moved quickly in play, but should not be denied this kind of activity.

We know that disabled children may not be able to move freely and explore their environment, so we must bring new experiences to them. Modern toys are too often made of soft plastic so it is important to introduce other textures. Wood, stone, metal and a variety of fabrics such as silk, velvet, wool and cotton should be introduced and the child encouraged to feel and handle them. Other contrasts include fur, pan scourers and pine cones – all part of life's rich experience. For a good way to enjoy feeling and identifying different textures a small plastic or material bag is needed. The bag should not be transparent so the child cannot see what is inside. Put 2 or 3 different objects into the bag. The child should put his hand into the bag and without looking should identify the textures or objects. Initially very different objects such as a sock, a hair brush and an apple may be used. As the child becomes more skilled at recognising these objects different ones may be substituted or added. It is more of a challenge to differentiate an apple from an orange, or socks from mittens.

Try to think of toys that stimulate other senses as well as touch. How about musical toys or others that make a noise? What about bright or contrasting colours, or shiny paper? These stimulate hearing and vision, which is very important. If a child has poor vision use contrasting colours. The best contrast is black and white, but blocks of bright colours are more easily seen than pastel shades. Other activities to stimulate hearing include nursery rhymes and short action poems and songs. These teach a child to listen and anticipate certain actions, help to teach certain parts of the

body and establish happy communication. As we said – play should stimulate and give pleasure to the child.

Dropping balls or other objects into a bowl is very satisfying as it makes a lovely noise. To play this game the child must look to locate a ball, move his arm towards the ball, open his hand, grasp the ball, move his arm while holding the ball, then release the ball on target. Quite a complex manoeuvre – and a great game! As a child becomes more skilled the container can be reduced in size to encourage more accuracy in placing the ball, the balls can be counted as they drop, or he can be asked to select a particular colour.

These toys and activities are suitable for children of all ages. As they mature children start imitating adult activities when they play. They love to push a small pram or trolley with a favourite toy inside, wash dishes in soapy water and sweep the floor. Again, disabled children may need help and encouragement, but they too can enjoy these activities. Pouring or scooping sand or water makes a lovely game and helps develop understanding of weight and gravity – early science lessons! “Pretend” games are another way to develop a child’s imagination as well as physical skills. Dressing-up in another person’s clothes and pretending to be that person is fun. Children like to play at shopping. One child can be the shop keeper and another child or an adult can be the customer. Various goods can be bought and sold, and if the child is able they can use this experience to learn about money. This game is useful for developing speech. Parents may be surprised to hear their child repeating phrases that they use regularly and had not realised that their child understood! When a child starts school he often repeats his new experience by acting as the teacher and making a school for his toys. It can be a useful way of preparing the child for a different activity such as having his hair cut or going to the dentist. If a parent first shows the child what will happen by playing the same activity with familiar toys the child will be able to learn what to expect.

Paper is a great toy. It can be folded to make kites, hats, aeroplanes, boats and many other objects. Coloured paper is good, but all these things can be made from newspaper at little or no cost. A sheet of paper can be folded, then torn or cut with scissors – another useful skill – to make a pretty table mat or snowflake. A line of dolls holding hands can be made in the same way. The dolls can then have clothes painted or crayoned on them.

Some children find getting dressed very difficult. It is always easier to take clothes off than put them on, so let him do this first. He may be unable to work out which way up a garment should be, and which arm or leg should go into which hole. Play can be most helpful here. Putting clothes on a toy is easier as the child can see more easily than when his own clothes are partly on himself. Putting necklaces over his head and taking them off again will prepare him for putting on a vest or jumper. Putting rings over his feet and legs will let him practice the movements needed to put trousers on.

Drawing with large crayons or painting with a brush or just fingers is another great play activity. This helps to develop fine motor movements and helps the child to express himself. Do not try to make him draw or colour tiny objects accurately, but allow him to make big areas of colour. Ask him what he has drawn and do not criticise his efforts; accuracy is not necessary but enjoyment is! Making biscuits or pies or playing with special “pastry” is much enjoyed and encourages hand movements. Simple puzzles and shape and colour sorting can be varied endlessly. How about finding all the blue cars, or sorting farm animals from zoo animals?

Research shows that play influences the development of all children. While some splendid toys are very expensive, many cost little or nothing. The attached list of ideas suggests toys costing no more than a few pence. Many of them can easily be made at home and I’m sure you will have plenty of other ideas. Remember you are all in a special position where **you** can influence the

development of disabled children by encouraging their parents to handle them therapeutically and suggesting appropriate forms of play to enhance their development. Without this advice some of these children will not achieve their full potential.

Low Cost Toys.

Shiny paper – mobiles, spirals, to cover shapes, handling and scrunching.

Plastic bottles with dried beans or pasta inside – shaking, rolling, making music.

Balls – different sizes and weights for rolling, catching, and sitting on for balance.

Wooden bricks for building – father can make some.

Sheets of paper – for folding into hats, boats, aeroplanes etc; for cutting or tearing into dolls or pretty mats.

Necklaces – made of buttons, uncooked pasta or beads. Think of colour and size contrast.

Sorting objects by colour – large buttons, cars.

Bubbles – for reaching to touch, for looking, for blowing, for bursting by clapping them.

Metal bowls – to sit in or drop things in – noise!

Mirror – for recognising self and learning nose, ears, eyes etc.

Dolls – for practicing dressing, for learning body parts, for pretend play.

Toys on wheels with string to pull – tie a large button on the end of the string to make gripping it easier.

Wheeled small toys – push + sound, imaginative play.

Musical toys – xylophone, drum, trumpet, bells.

Shape sorter – can be made of cardboard, lino or sheet polystyrene.

Textures to feel – fabrics etc in bottom of large plastic bottle or in a bag.

Objects to identify – unseen in a bag.

Cotton reels – for stringing, threading and building.

Squeaky toys – these have limited value. Many are too large for small hands to squeak.

Play dough or pastry – for model making, messy play. Good 2 handed activity.

Sand or water – for pouring, scooping and pretend play. Good 2 handed activity.

Puppets – made from socks or fingers from old gloves. Good for encouraging speech and pretend play.

Tips for professionals about how to interact with disabled people

Many non-disabled people are ill at ease when interacting with disabled people. They may be nervous about accidentally causing offence, or scared because they don't know how to communicate and afraid of misunderstandings. There are some simple rules that can help those who are uncertain about how to behave.

The main principle is to treat everyone with courtesy and respect, including disabled people. Treat each person as an individual, with her own way of interacting.

Other general guidelines include:

- Speak directly to the person, in the same way as you would to anyone else, not to her parent or assistant.
- Speak normally and clearly. Don't rush your words, shout or mumble. If you are talking to a person with limited hearing, check that she can understand you.
- Get on the same eye level, and look the person in the eyes (**Nazgul: assuming this is culturally appropriate????**). This is the best way of making sure that your attention is on her and what she is saying.
- Don't treat a disabled adult like a child. Talk to her like an adult. A person's impairment may prompt your concern – but don't restrict her freedom.
- Offer assistance, but don't help someone without asking first. If you are helping someone, always do what she asks you, not what you think is best.
- Try not to stare if something about the person seems unusual to you – while many disabled people are used to being looked at, staring will make anybody self-conscious and uncomfortable.
- Avoid language that you know is rude or derogatory. When talking about people, refer to them by their name rather than their impairment.
- Be polite. Treat the person the same way as you would anyone else.

Disabled people have also suggested more specific guidelines for different kinds of impairment:

Interacting with people with mobility impairments

- Treat people with courtesy and respect. For example, don't leave someone behind by walking off too quickly.
- Just as you wouldn't lean on a person you are talking to, don't lean on someone's wheelchair or other mobility appliance.
- If you are offering assistance, ask before you do anything. In general, move the obstacle (whatever is in the way) rather than the person.
- If you are asked to carry someone, check with her where it is OK to hold her (or her wheelchair/appliance). Always do what she asks you, not what you think is best.

Interacting with people with hearing impairments

- Treat people with respect. If the telephone rings or there is a knock at the door while you are talking to a Deaf person, excuse yourself and explain what you are doing. Don't leave her sitting there with no explanation.
- Find out how the person likes to communicate – there are a variety of different ways, including speech, sign language, finger spelling, writing or gestures and body language. Each person will use the combination that suits her best.
- If you are talking to a person who is lipreading, some simple tips to remember are:
 - Get the person's attention before speaking – by calling her name, touching her arm or waving.

- Make sure that the person knows the topic of conversation: this is particularly important for lipreading, as many words look very similar, and Deaf people who read lips depend on context to pick out key words.
- Speak slowly and clearly – but don't shout or exaggerate words, as this will make it much harder to lipread.
- Look directly at the person and maintain eye contact.
- Don't cover your mouth or put anything in it while talking.
- Stand so that your face is clearly lit – not in shadow or in front of a bright light, as this makes it harder for the person to see your mouth.
- Use short sentences.
- Use gestures, body language and facial expressions to help get your message across.
- If you aren't making yourself understood, repeat yourself once. If this doesn't work, try again using different words. If that doesn't work, write it down.
- Use open questions that require more than a 'yes' or 'no' answer. The response to an open question will allow you to make sure that the Deaf person has understood you.
- Many Deaf people communicate with hearing people by speaking. If you find it difficult to understand something a Deaf person has said to you, ask her to repeat it or offer her a pen and paper to write it down. If you are communicating by writing things down, some of the same principles apply:
 - Establish the topic of conversation first.
 - Use short sentences or phrases – it isn't always necessary to write down every word.
 - Write legibly and clearly – printing each letter separately is usually best. If you are in an office setting, it may be possible to use a computer instead.
 - Use open questions.
 - Face each other after writing down each phrase – eye contact and facial expressions will make your communication much easier.
 - Use drawings and diagrams to get your message across.
- Even if you are communicating through a sign language interpreter, it is important to remember that you are still talking to the Deaf person. Talk directly to her, not to the interpreter – for example, 'what do you think?' not 'what does she think?'
- Remember that sign languages are languages in their own right – for many Deaf people, their first language is a sign language. Different countries have different sign languages, and in many cases different regions have their own dialects, as with spoken language. Learning some simple signs, such as greetings, is a basic courtesy like learning any other language.

Interacting with people with visual impairments

- Speak directly to the person, not to her assistant or companions, and speak normally and clearly. Remember that people with visual impairments do not necessarily get the extra information that you may take for granted – so always explain what is going on.
- Tell the person when you arrive and when you leave.
- Always introduce yourself by name ('Hello Aigul, it's Timur') and explain why you are there.
- When you first speak to the person, a gentle touch on her arm lets her know that you are talking to her; a handshake helps orient her to where you are.
- If you are in a group, explain who else is with you. Identify yourself each time you speak.
- Use the person's name often, to make it clear when you are speaking to her.
- Describing the environment:
- Be specific in giving directions. Do not say 'over there' or 'over here'. Instead say 'on your left or right' or 'immediately behind' or 'in front of you'.

- When a blind or visually impaired person arrives at a new place, tell her who is there, and offer to describe the environment. Make sure that you describe any obstacles or hazards, and whether there are any children or animals around.
- Do not leave the person alone in the centre of a room. Make sure she can touch a table, chair or wall to maintain orientation to her surroundings.
- Be safety conscious, but don't limit the person's freedom. Move the obstacles, not the person.
- A visually impaired person may not describe her environment in the same way that you would. This may reflect limited depth perception or an inability to see shapes or shadows. Discuss the images she describes so that you can both understand each other.

Guiding a blind or visually impaired person:

- Always ask the person if she would like assistance first.
- Always speak first – never take someone's arm or hand without warning.
- If the person does want help, ask her where she wants to go.
- Offer your arm for the person to hold just above the elbow. This will allow her to walk slightly behind you, following you as you turn or step up or down.
- Walk normally – not too slow and definitely not too fast.
- Whenever you come to a turn, a step or an obstacle, pause and tell the person what is coming.
- Guide the person round chairs and through doorways, explaining what you are doing – she will be slightly to one side of you, so give more space as you go round obstacles.
- Don't try to sit her down – just guide one hand to the back or arm of a chair, or to the edge of a table.

Interacting with people with learning difficulties

- Treat each person with respect and be sensitive to her individual needs and behaviour.
- Different people find different things difficult. Find out each person's preferred way of communicating (how she likes to speak and be spoken to, how she likes to be touched or not).
- Sometimes people with learning difficulties may behave in unusual or surprising ways.

sensitive to how you behave and how your actions might cause someone to react – don't panic or respond aggressively.

People with learning difficulties may take more time to understand or respond to what they hear. Some people may find it difficult to concentrate. It might be helpful to think about the ways you communicate with people who do not have the same first language as you, or who are illiterate. In general:

Speak normally and clearly.

Use simple, short words – if you have to think about what a word really means, don't use it.

Use real-life examples and words for real things – people with learning difficulties may find abstract concepts difficult.

Use short sentences and express one point at a time – people with learning difficulties may find it difficult to remember a list of different things.

Give the person time to take in what you have said and time to respond – don't rush into repeating yourself.

If you aren't making yourself understood, repeat yourself once. If this doesn't work, try again using different words.

Sometimes it helps to emphasise the most important words in a sentence.

Use more closed questions with clear options, rather than an open question with many possible answers.

If you are asking someone with learning difficulties to make a significant decision, it may be best to give her some time to think on her own or with her main caregiver.

Food and Feeding.

Why do we need to know about food and feeding? The food we eat provides us with the energy we need to live. The amount of energy we need depends on 2 things; our level of activity, and our own size. If we are more active, we need more energy to keep going. If we are bigger and heavier we need more food than someone who is smaller and lighter. We can see this by walking up stairs. If we walk up 2 or 3 flights we are not too tired, but if we walk up 7 or 8 flights we feel tired from our effort. If we carry a small bag it is not too difficult. If we carry 2 heavy bags up the same stairs we feel tired much more quickly, and use more energy to achieve this task. Women need around 2,000 calories daily to maintain a healthy weight. Men need a little more – around 2,500.

Children also need more food if they are active than if they lie quietly. A child with athetoid cerebral palsy needs considerably more food than a child with low muscle tone. The constant movement associated with athetoid cerebral palsy uses a lot of energy which needs to be replaced by eating regularly. These children often have difficulty eating due to problems chewing and swallowing, so they usually need 5 smaller meals every day rather than 3 larger ones. They also need small snacks after periods of activity such as physical exercise and play. When children with spastic cerebral palsy are playing actively they too need more food as their tight muscles work harder constantly unlike normal muscles which relax frequently.

The food we eat provides us with a wide range of nutrients. The 3 main food groups are proteins, carbohydrates and fats / oils. We need some of each of these food types daily to stay healthy. Protein gives us the nutrients we need for our bodies to grow and to repair any tissue damage. Protein is found in meat, fish, milk, eggs, cheese, nuts, cereal grains and vegetables such as lentils, beans and peas. Carbohydrates give us the energy to move. They are converted to fuel in our muscles, but if we eat more than we need for activity they are stored as fat. Carbohydrates are found in bread, biscuits, sugar, honey, and all cereal grains including rice, buckwheat, semolina, oats and barley. Fats come from either animal or plant sources. Those from animal sources include butter, cream, egg yolks, hard cheese and the fat in meat. These should be limited as excess animal fats can coat the inside of blood vessels around the heart leading to heart attacks. Plant oils such as sunflower and olive oil cause less damage to our bodies. We need fibre in our diet for good functioning of our intestines. This is found in fruit and vegetables.

Other important nutrients come in very small quantities. Vitamins and minerals are needed for chemical reactions in our bodies, and shortages of these lead to specific problems. Vitamin C is called the sunshine vitamin as it is present in ripe fruit and vegetables but is water soluble and is destroyed by prolonged cooking. It is particularly concentrated in citrus fruits such as oranges, mandarins and lemons but also found in other fruits and in potatoes. It is needed for tissue repair and to prevent us catching colds and flu. Vitamin B is found in yeast and wheat germ and is necessary for a healthy nervous system. Vitamin A is found in carrots and other orange vegetables and is needed for good eye function. Vitamin D is found in milk and some plant oils and can be made on our skin when we are in the sunshine. Lack of this vitamin leads to weak and misshapen bones, particularly in the lower legs. This is called rickets. There are many more vitamins and minerals needed for healthy living. By ensuring we eat a varied diet containing plenty of fresh fruit and vegetables, some protein, and not too much fat, we should stay healthy. When a good variety of food is not available it may help to take a multivitamin supplement to ensure adequate micronutrients. Young children have different needs for vitamins and minerals and should not be given tablets designed for adults, but those specifically for children.

We know that a person can manage without food for several weeks in a crisis, but what do we need more than food? Yes, liquid. We die if we are without liquid to drink after a few days, particularly in hot weather. The recommended amount of liquid for an adult or teenager is 1.5-2 litres every day. How many of you drink this much? Alcohol does not count as it uses body fluid to be

absorbed. Strong tea and coffee act as a diuretic – this means that they cause our body to get rid of water through the kidneys. So we can see that large quantities of tea and coffee do not help our fluid intake. We need to drink clear fluids – and I do not mean vodka! If we exercise, or in hot weather, we sweat and this means our body is losing water to cool us down. What should we do then? Correct – drink more water! Although it is very cold in the winter months here in Astana our living areas are usually heated to a summer temperature so we still need to drink plenty.

All this also applies to the children we work with. When a baby is young he is usually breast fed on demand, and this is the best and safest method, with a few exceptions. His mother's milk is designed specially for human babies. It is produced at the correct temperature and contains all the nutrients a baby needs. It also passes immunity to some infections from the mother to her baby. It is clean and produced according to demand. To ensure a good supply the breast feeding mother needs to drink plenty of extra fluid and eat a good and well balanced diet. Nature has a way of ensuring the baby survives. The baby is a parasite. It takes what he needs to grow from his mother's body. If there is not enough of a specific nutrient, the mother will suffer initially and not the baby.

There are few occasions when breast feeding is not the best option. The main one is if the mother has an infection, as this could be passed to the baby in her milk. One particularly devastating infection is HIV / AIDS. This can be passed to the baby in breast milk, so if the mother is HIV positive she should not breast feed her child. Breast milk from another mother can be used and given in a bottle, or artificial milk specially produced for babies can be used. A few severely disabled young babies are unable to breast feed as they may be too disabled to suck. In this case a tube is usually passed down the throat to the stomach so milk can be given without the need to suck and swallow. Breast milk from the mother should be used if possible and normal feeding introduced as soon as the baby can manage this.

As our baby grows he needs more food and nutrients than a mother can provide herself. Weaning starts at 4 or 5 months when other foods are introduced. In the UK some form of cereal is usually the first food given. This can be mixed with breast milk. Soon pureed fruit and vegetables can be given to provide a varied diet. By 6 months a baby can grasp an object and take it to his mouth. This is a good time to start finger feeding. A piece of bread baked in the oven may be given to the baby for him to suck and chew on. This will help his first teeth to come through the gums. Pressure on the gums leads to healthy teeth forming within the gums. Good sized pieces of hard vegetables are also good for the baby to chew on, but he should not be left alone with solid food in case he chokes.

Different tastes should be introduced to the young child rather than mixing everything together. By around a year old roughly mashed food including minced meats should be introduced. Soon the child can hold a spoon and start to feed himself. At first his mother will need to help him, but by the age of 2 years he should be self feeding with little problem. Although children like sweet things their intake of sugar should be restricted as research shows that sugar rots teeth as well as making us fat. Sugar provides only calories with no vitamins or minerals and is not needed in our diets. Research also shows that babies and young children who get too much sugar are more likely to develop diabetes and heart disease later in life.

Now we have thought about food and drink we need to consider the process of feeding – how we take in this nourishment. Babies are usually breast fed in their mother's arms. This is typically in a position where their body is nicely curved in a little flexion and their head slightly higher than their stomach. This position will allow gravity to help the food reach their stomach easily. Babies usually reach one hand forwards to touch their mother's breast. If a baby is disabled his arm may need to be supported in a forward position as this will help him to feed better. Why is this? If his arm drops back he will tend to extend his neck and this will make it very difficult for him to

swallow. Put your head back now by looking at the ceiling, then try to swallow – very difficult, isn't it! When eating or drinking our head needs to be held forwards as swallowing is a flexion activity. This means that it is facilitated by a flexed body position.

This important fact needs to be remembered whenever a child is feeding. A young child starting to feed from a spoon needs to come forwards for his food, not be fed lying back in extension and having it poured down his throat. This will lead to swallowing air and choking as the food may pass into the lungs rather than to the stomach. You should all now have copies of the leaflets for parents. The 3rd one which is pink gives basic advice on feeding and drinking. Most of the information is not new to you. We know that we can reduce spasm and stiffness by controlling the position of his legs and body, so keeping a young baby's legs apart and his head forward will achieve this. As swallowing is a flexion activity, applying gentle pressure to the front of the chest will flex him and help him to swallow.

Some children will need support to keep their mouth closed while eating. This is shown on the leaflet, and in more detail in the Nancy Finnie book. The type of spoon used when starting to spoon feed is important. It should be rounded and fairly flat. Pointed spoons may stimulate a tongue thrust reflex when the tongue pushes forwards and so pushes food out of the mouth rather than allowing it to be swallowed. If the spoon is too deep it will be difficult for the child to take the food off the spoon. The food should not be scraped off on the upper teeth or gums but actively taken with the lips by the child. Patience may be needed to help the young disabled child to learn to do this. It may take a normal child several months to master spoon feeding so we must expect it to take longer for a disabled child.

The child should always be able to see his food, so the dish must be placed in front of him. The spoon should be given from the front and pressed firmly onto his tongue to control any tongue thrust. Only small amounts of food should be given on each spoon initially and it should not be too liquid or it may run out of his mouth too easily. If the food is placed slightly to the side of his mouth a child will need to use the muscles of his mouth and tongue to move it to the correct position for swallowing. This will also prevent reflex swallowing and choking. When learning to chew a child may need help and support to keep his mouth closed. It is important to achieve chewing to ensure he gets sufficient nourishment as he grows older. Good eating patterns are important to enable a child to be socially accepted.

As soon as a child has head control he should be fed sitting in a small chair rather than on his mother's lap. His hips, knees and ankles should be flexed to 90 degrees and his feet should be supported to give him a stable base for the fine motor movements needed to feed himself. Either a small chair can be used at a small table, or a small chair on long legs can be used at the family table in the kitchen. Let his better hand hold the spoon, and make sure that he grips it correctly. The spoon handle should be between his thumb and index finger. His other hand should be well forward to prevent extension spasms, and he can be encouraged to use it to hold his dish steady.

Learning to drink from a cup can be quite a problem for some children. In Astana I keep hearing that children of 5 or 6 years are drinking only from a spoon. It is not possible for a child to get enough fluid each day if he drinks only from a spoon. By the age of 9 to 12 months all children should be drinking from a cup as well as from the breast or a bottle. Initially a child's tongue may get in the way, but with practice all children should learn. Again the child should be sitting comfortably in a well supported position. The cup should be presented from the front, not from above, and should not be removed after every mouthful but left resting between his lips. In order for a parent to be able to see what is happening it may help to cut out a section of a plastic beaker. Any support from the parent should be round the child's shoulders as pressure behind his head may stimulate unwanted extension.

If these ways of feeding are started at the correct stages of a child's development they are usually not difficult to introduce. When the parent and child have got into bad habits it may be more difficult to introduce good feeding patterns. We need to persevere for the sake of the child and his family as eating and drinking are social activities as well as ways of getting sufficient nourishment.

Good eating and drinking patterns will also help the development of speech as the same muscles are used in these actions. A normal 6 month old child dribbles and takes everything to his mouth. He makes only single or double sounds when trying to communicate. By the age of 12 months he is starting to make sounds in the tune of speech, and saying simple words. He is no longer dribbling all the time as he gains control of the muscles of his mouth, face and throat. By the age of 2 years he can say around 50 words, can feed himself and is no longer dribbling. These activities are all closely connected and develop simultaneously.

We need to remember, and to teach parents of the children we work with, that good patterns of eating and drinking can be developed by all children. A child needs to be in a well supported and comfortable position for feeding and should be encouraged to feed himself whenever possible with as much help as is necessary. Adequate nutrition and fluid intake is difficult to achieve if the child does not learn to eat a good variety of solid food and to drink from a cup. Developing good patterns of eating and drinking will help speech to develop as the same muscles are used in these activities. To be socially accepted a child needs to be able to eat and drink tidily and this is best achieved before the child is 3 or 4 years old.