

MODULE 12

# CHILDREN WHO DEVELOP DIFFERENTLY

children with disabilities or  
developmental difficulties





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## KEY MESSAGES - why is this topic important for you?

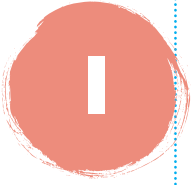
- Disabilities and developmental difficulties are common everywhere around the globe. This means that you are likely to meet children with disabilities and/or developmental difficulties when you visit your families.
- For newborns or young children with disabilities or developmental difficulties, the early days and years are just as, or even more critical to help children achieve their full potential. As a professional of trust, your role is key to support the family and the child, listen to their concerns about the child's development, to sign post them to the appropriate services, support them in using these services, and to promote the full social inclusion of the child and family in the community.
- Sometimes you will visit families with young children whose parents already know that their children have developmental difficulties or disabilities while at other times you will be the first to notice that a problem exists during your visit. Understanding the causes of disabilities or developmental difficulties and the importance of early identification and intervention will help you support the families and their children.
- An important part of your health visiting role is to contribute to the prevention of disabilities and/or developmental difficulties, as well as to the optimal growth of infants and young children who are living with disabilities or experience developmental difficulties. Children with disabilities and/or developmental difficulties who receive additional attention and support are more likely to reach their full potentials.
- By observing the child, listening to parental concerns, using your knowledge of typical child development, and drawing on your professional experience, you may be the first professional to detect that a child appears to be delayed or is experiencing some difficulties in daily functioning and development.
- You should share your observations with the parents in an empathic way. It is important for you to encourage parents to ask for and receive professional help so that they can provide a stimulating and inclusive environment that meets the child's particular needs for development.
- You play a very important role in helping parents to accept reality, cope with feelings of guilt and inadequacy, and to empower them to enjoy the interactions with their child.



## LEARNING OUTCOMES

By the end of this module, you will be able to:

- Have an understanding of some of the causes of disability and developmental difficulty from conception through the early years
- Understand the contribution you can make to prevention, early identification, and intervention for young children with disabilities or developmental difficulties
- Have knowledge about common issues faced by families with children that have disabilities or developmental difficulties
- Learn about providing this group of families and children with the support they need
- Know how to utilize the resources that are available to you and the family and understand the importance of working with other professionals to support children with disabilities and their families.
- Be aware of your own feelings and perceptions of children with developmental difficulties and their families and reflect on them.



## INTRODUCTION



### Reflection and discussion

Here are some questions for reflection and discussion

A. Look at the pictures of four individual with disabilities. What expectations would society have of these individuals? Can individuals with such disabilities make important contributions to society?



Individual A was born with Down Syndrome



Individual B was born with Cerebral Palsy



Individual C was diagnosed with amyotrophic lateral sclerosis (ALS) at age 21



Individual D contracted polio at age four



To find out more about these individuals and several other people with disabilities. You can find more about them in the **Information card 1**. Their stories remind us that a diagnostic label does not define how an individual functions in daily life. Many children will far exceed our expectations when they receive the necessary love and support and are allowed to achieve their true potential.

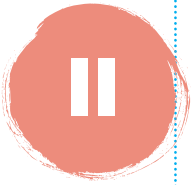
B. Do you know or have you heard of individuals in your country and community that have overcome conditions considered handicapping and achieved more than expected by the people around them? How did they manage to do so? What do you think was the role of their families and the professionals supporting them?

C. Your role as a home visitor is challenging, but contributes significantly to each of your families and society in the long run. If you have worked for a number of years, think how your advice and support may have contributed to preventing a disability or developmental delay? Have there been times when you were able to contribute to improving parent-child interactions or the home environment for better development outcomes? If you still lack experience, what are some situations where you could contribute to better outcomes?

Before learning more about disabilities, developmental delays, and developmental difficulties and your role in prevention and supporting families, it is important to keep in mind that all of us have abilities/strengths and weaknesses. Many of us have learned to use our strengths to compensate for areas where we feel more limited. As illustrated in Exercise 1, some individuals with significant disabilities manage to excel because of strong support from their families and professionals like you.



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## THE PREVALENCE OF DISABILITIES AND DEVELOPMENTAL DIFFICULTIES

As defined by WHO and UNICEF (2012), “disability can occur at three levels:

- An impairment in body function or structure, such as a cataract which prevents the passage of light and sensing of form, shape, and size of visual stimuli;
- A limitation in activity, such as the inability to read or move around;
- A restriction in participation, such as exclusion from school.” (WHO & UNICEF 2012).

At the time of birth, limitations may not be evident, but for many medical conditions professionals know that there is a high risk that certain limitations in activities and participation will occur later on. Parents may also be aware and be anxious, afraid, and upset. The earlier you start supporting the parents and the child’s development to reduce limitations in functioning, the easier it may be for the child and family to be socially included.

WHO and the World Bank estimate that about 15% of the world’s population experiences significant difficulties in functioning, less than 5% have clearly defined disabilities.

### **Why are we so unsure about the number of children affected?**

The prevalence rates (or per cent of children affected in a country) varies from country to country. This is due to the fact that the term “disability” and “developmental difficulties” are defined differently in the countries around the globe. It depends on what types of conditions are included. For example:

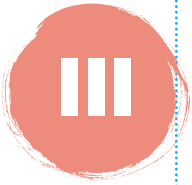
- A recent study in the US included attention deficit hyperactivity disorder; intellectual disability; cerebral palsy; autism; seizures; stuttering or stammering; moderate to profound hearing loss; blindness; learning disorders; and/or other developmental delays and obtained the figure of 15 per cent.
- Across 25 countries in Europe, 21 per cent of children are reported to be affected by medium or high levels of psychological difficulties (Rivera, 2014).
- A review of disability in low and middle-income countries in 2007, reported numbers ranging from less than 1 per cent to almost 20% and concluded that there are significant gaps in knowledge (Maulik & Darmstadt, 2007).

Much less is known about the proportion of children under two that are affected or at-risk for a number of reasons:

- The early identification systems of a number of countries do not have and/or use an agreed upon classification system and standardized valid assessment tools.
- Some developmental delays become apparent over time, for example in preschool or during the early school years (e.g., stunting, socio-emotional/mental health problems, Autism Spectrum Disorders, intellectual disability) or when certain skills are required by the environment (e.g., Attention Deficit Disorder, Learning Disability, Dyslexia), and
- Increasingly, we are also becoming aware of the serious impact of a caregiver’s mental illness (e.g., maternal depression during pregnancy and/or the early years) on the young child’s developing brain, development, and wellbeing.



Overall, it is safe to assume that about 1 in 6 children will encounter some developmental difficulties.



## WHAT ARE DISABILITIES AND DEVELOPMENTAL DIFFICULTIES?



### Reflection and discussion

Here are some questions for reflection and discussion:

- A. The terms that are used to describe and “label” individuals with disabilities or developmental difficulties have changed and are continuing to change. What are some of the terms or labels that were used in your country in the past, that are no longer acceptable? (Each country needs to prepare a list of terms used and the correct ones).
- B. Put yourself in the position of a parent with a child with disabilities and think how you would feel if you heard these terms or labels?
- C. Why is it so important to be aware of the changes in how terms are used and to use the correct terms?

### SUGGESTED ANSWERS FOR C:

- Labels often have negative connotations attached to them and stigmatize the individual, i.e., set the individual apart from others
- Labels can change our expectations of what an individual will be able to achieve
- Labels may exclude the labeled individual from opportunities and services



### Self-assessment

Give true/false answers to the following questions:

1. Children cannot have developmental delays in the socio – emotional domain of development.
2. A child diagnosed with a developmental delay will always lag behind his/her age mates.
3. Children growing up in conditions of social disadvantage (poverty, violence, etc.) will always be delayed in their development.
4. Children with the same diagnostic label may differ in their developmental outcomes, i.e., how well they do in life.
5. Terms “developmental disability” and “child with developmental disability” have the same meaning.

### ANSWERS:

- 1. FALSE!** Young children may experience developmental delays in their general physical growth, in socio-emotional, language, and cognitive development, and in their ability to manage their own behaviour.
- 2. FALSE!** With the right support early on, some children with delays can catch up. The right support will help each child!
- 3. FALSE!** Effective and responsive parenting overcome some of the effects of poverty and help young children keep on track with their development.
- 4. TRUE!** The same disability (diagnostic label) covers very different abilities of the child. How the child will do in life depends on the child’s abilities and the level of support provided by the family and environment. *For example, one child with Cerebral Palsy can be very gifted, but without the appropriate support he/she will not reach be able to demonstrate his talents. Another, less gifted child with Cerebral Palsy, but with a nurturing and supportive environment, will be able to express her talents, receive recognition and develop self-confidence. The same can be observed in children with typical development.*
- 5. FALSE!** A child with a developmental disability is a person, and the term “developmental disability” is only one of the specific conditions the child has.



## Definitions

**Children with disabilities.** Children up to the age of 18 who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. (Convention on the Rights of Persons with Disabilities, Article 1)

**5 developmental areas:** communication/language, motor skills (fine and gross), social-emotional development, self-help skills/adaptive skills.

**Developmental disorder or developmental disability.** Developmental disorders or disabilities are a group of conditions associated with an impairment in physical, learning, language, or behavioral areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime.<sup>1</sup>

**Developmental delay.** Developmental delay has been defined as "a deviation of development from the normative milestones in the areas of cognitive, language, social, emotional and motor functioning (WHO, 2012, p. 2)." Children develop at different rates. Delays in development can be due to disabilities, but also to a host of other conditions. Some developmental delays may improve with intervention and can even disappear. Delays can be general that is all developmental domains are equally affected, and the child's development is like the development of a younger child. The delay can be variable, some domains may be more delayed than others (e.g., language or socio-emotional), or atypical where the child develops differently in both the rate of development of a domain and the quality (e.g., a child who can memorize a dialogue heard on television, but cannot ask for a food item).

**Developmental difficulty.** The term children with developmental difficulties is supposed to "encompass all children who have limitations in functioning and developing to their full potential" (WHO, 2012, p. 2). This may be due to disabilities, social deprivation, or other conditions.

**Developmental milestones.** Skills such as taking a first step, smiling for the first time, and waving "bye-bye" are called developmental milestones. Children reach milestones in how they play, learn, speak, behave, and move (for example, crawling and walking) at approximately the same age. <http://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html>

**Social inclusions.** Social inclusion is both an outcome and a process of improving the terms on which people take part in society. <http://www.worldbank.org/en/topic/socialdevelopment/brief/social-inclusion>

In your work, you will see children "that are born with a disabling health condition or impairment, while others may experience disability as a result of illness, injury or poor nutrition. Children with disabilities include those with health conditions such as cerebral palsy, spina bifida, muscular dystrophy, traumatic spinal injury, Down syndrome, and children with hearing visual, physical, communication and intellectual impairments. Some of impairments can be observed at birth or even before birth (for example Down syndrome or spina bifida), some of them are not (for example autism spectrum disorders or intellectual impairment). This is the reason why monitoring child development and listen to parental concerns are so important.

Severity of disability ranges from mild (child is fully able to participate, with minimal support to severe (the child needs a complex support system to participate and be fully included in society). Some children have single impairments while others may experience multiple impairments. The complex interaction between a health condition or impairment and environmental and personal factors (WHO & UNICEF, 2012, p. 7) means that we can never know in advance how well the child will develop. Each child and family deserves the best possible support.

Just like typically developing children, children with disabilities or developmental difficulties can develop their full potential in the right environment. Consider for example a child with a hearing impairment, who is

raised in a nurturing family that talks to her and uses sign language for communication. This child may be on track with respect to all the developmental milestones. Another example may be child with Down syndrome who is receiving support with comprehensive development and who despite some intellectual impairment can participate actively in a regular preschool.

Children born with disabilities that live in poverty and are exposed to violence or neglect in the family are in the most difficult situation. We know that young children with disabilities are likely to be more vulnerable and in need of adequate support in comparison to typically developing children.

On the other hand, children with no obvious disabilities or no disabilities at all may be born into situations of social disadvantage or go through adverse experiences during their early years and experience developmental difficulties. For example, we now know that the development of young children can be seriously affected by being exposed to violence (both by violence they experience themselves or violence against others they observe), or by being cared for by a caregiver suffering from depression or other mental illness. Poverty can also contribute to developmental difficulties, however responsive and nurturing parenting and a stimulating home environment can buffer against the effects of poverty and other adversities.



**Your role in these cases can be crucial!** You will want to promote the happiness and wellbeing of all children, including those at risk and with disabilities. You can help family recognize risk factors but also developmental needs of the child and support them as they deal with these. Observe the child's development and make an informed decision of whether you consider the child at risk of a delay; refer the family to the necessary assessment services; support the family in their work with intervention specialists, and help them enjoy their children and their developmental achievements.



### Case study

A young couple's baby was diagnosed with Down syndrome at birth. They started to blame each other for the child's condition and developed marital problems. With time, they became overwhelmed with their personal conflict and their new financial difficulties. They only gave basic physical care to their baby and did not play with her or cuddled her.

The home visitor noticed the marital problems but also the neglect. She conducted additional visits, modeled how to play with the baby, demonstrated nurturing care, tried to encourage the couple to ask for help regarding their marital problems and parenting, contacted a referral agency, but was not successful. Around the baby's first birthday, the couple decided to give the baby up for adoption. At that time, the baby was tiny, very often ill, did not eat well, and only lay in her bed, apparently without interest in her environment.

In the new family, with very nurturing parenting, the support of the home visitor, and early childhood interventionists, the baby started to blossom. Now, she is an active and social girl attending first grade in a mainstream school and enjoys her everyday life in school and in her family.

Questions: What else could the first home visitor have done? How would you have proceeded? Discuss lessons-learned from this case with your colleagues.

**Common Developmental disorders or developmental disabilities**

Condition	Functions/ developmental areas affected	Explanation
Cerebral palsy, neural tube defects	Motor skills Other developmental areas (communication, cognitive skills, self-help/ adaptive skills, socio-emotional development) also can be affected	<p>Cerebral palsy is caused by damage to the brain before, during, or shortly following birth and is the most common cause of mobility problems in childhood. It affects body movement and muscle coordination. Individuals may also experience seizures, speech, hearing and visual impairments, and mental retardation, and may not be able to walk, talk, eat, or play in the same ways as most other children. Although cerebral palsy is a lifelong condition, interventions can help improve the child’s ability to function.</p> <p>Neural tube defects are birth defects of the brain and spinal cord. Neural tube defects happen when the neural tube does not close completely. This can cause serious problems, including death. Spina bifida is the most common neural tube defect. Children with spina bifida may have paralyzed legs and problems controlling their bladder and bowel.</p>
Intellectual disability	Intellectual/cognitive functioning Adaptive skills/self-help skills Communication Social skills Learning rate Attention Memory Motivation	<p>Individuals with intellectual disabilities have mild to profound limitations in their intellectual functioning and adaptive skills (communication, conceptual skills, social skills, self-care, etc.). Standardized tests are used to assess an individual’s strengths and challenges. Individualized will promote optimal development, education, and self-care with a goal for independence and social inclusion.</p> <p>Down Syndrome is a chromosomal abnormality that results in mild to severe intellectual disability. Speech and language may also be delayed. Children are often diagnosed at birth due to certain physical characteristics (facial features, large tongue, heart problems, and poor muscle tone). This condition can be ameliorated with educational and behavioral interventions, speech and language therapy, and behavioral interventions.</p>
Autism Spectrum Disorders	Interaction with people Social-emotional development Communication, Self-help/adaptive skills	<p>Autism spectrum disorders are defined by deficits in three core areas: social skills, communication, and limited, rigid, self-stimulating behaviors and/or interests. Abilities in core areas differ widely across children in their intensity, symptoms and behaviors, and types of disorders. Children with autism spectrum disorders may be non-verbal and not engage with people or high-functioning (i.e., Asperger Syndrome), with idiosyncratic social skills and interests. It is often stated that children with autism spectrum disorder learn in different ways, i.e., that their brains are wired differently.</p>

Condition	Functions/ developmental areas affected	Explanation
Expressive language disorder, Receptive language disorder, Stuttering	Communication Social skills	<p>An expressive language disorder is a condition where a child has problems expressing him/herself in speech (e.g., limited vocabulary, difficulty recalling words, difficulty producing longer or more complex sentences).</p> <p>Children with receptive language disorders (often called Specific Language Impairment - SLI). Children have problems with language acquisition and language understanding. The combination of both conditions (expressive and receptive language problems) is also very common.</p> <p>Stuttering is seen as problem with fluency of speech (for example: repetition of syllables or sounds particularly consonants).</p> <p>Children often start speaking late and their difficulties in expressing themselves may interfere with relationships and learning. Speech and language therapies and social skills therapies may be needed.</p>
Hearing or vision impairment	Sensory Communication Social skills	<p>The senses provide the first modalities for infants in discovering the world around them.</p> <p>A child with hearing loss cannot hear sound in one or both ears. Hearing loss can range from mild (can't hear soft speech), severe (can't hear very loud sounds), to complete (can't hear anything at all). Hearing loss present at birth is called congenital hearing loss. Hearing loss also can develop later in life.</p> <p>Vision impairment. According to WHO moderate visual impairment and severe visual impairment are grouped under the term "low vision": low vision taken together with blindness represents all visual impairment. Most children are visually impaired due to refractive errors, which can be diagnosed and corrected. A small percentage are blind for the rest of their lives and need visual rehabilitation interventions for a full psychological and personal development.</p>

Condition	Functions/ developmental areas affected	Explanation
Emotional/ Behavior Disorder	Social skills Social-emotional development Communication	<p>Emotional /Behavior disorders are defined by externalizing (yelling, cursing, aggression, fighting, ignoring adults, lying, stealing, destroying property, hurting animals and others, sever temper tantrums, etc.) and/or internalizing (withdrawn, antisocial, daydreaming and fantasising, extreme fearfulness, nervous, self-harm, etc.) behaviors that fall beyond the norms of their culture and age.</p> <p>Emotional disorders are defined by difficulties to create and maintain interpersonal relations with peers and adults, inappropriate types of behaviors and emotions in common situations, excessive fears of common situations, people, objects, animals, etc. Disorders that fall under this category are selective mutism (children who selectively talks with family but not in other situations or with other people), generalized anxiety disorder (excessive unrealistic worries, fears and tension), phobias (extreme fears), depression, schizophrenia, Tourette syndrome (motor and vocal tics), Obsessive/Compulsive disorder, etc.</p>
ADHD/ADD Attention Deficit /Hyperactivity Disorder Attention Deficit Disorder	Attention Social skills Motivation Communication Self-management/self-help	<p>Children with ADHD or ADD have persistent patterns of inattention, difficulty focusing and/or hyperactivity and impulsivity at higher rates than typically developing same age peers.</p> <p>Children often have difficulties following vocal directions, difficulty attending to tasks and activities, are easily distracted and have difficulties organizing their space, behaviors and materials during activities. These difficulties have an affect on their learning.</p> <p>Hyperactivity and impulsivity is observed through constant and excessive fidgeting, restlessness, excessive loud noise production, difficulties waiting for their turn to talk or play, impatience, rushing through activities, lack of any self control and restrain.</p>
Multiple disorders		Some children may have multiple disabilities, e.g., a child with cerebral palsy and an intellectual disability

## IV

## A MAJOR SHIFT IN HOW WE LOOK AT DISABILITIES AND DEVELOPMENTAL DIFFICULTIES TODAY



### Self-assessment

Please answer the following true/false and multiple choice questions:

1. For children with moderate and severe disabilities, residential settings provide the most efficient and human way of care. The professionals there are trained to meet the particular needs of these children T/F
2. What factors does the International Classification of Functioning, Disability and Health (ICF) take into account when looking at disability?
  - A. The child's health condition (e.g., Down Syndrome) and personal factors (the child's way of learning)
  - B. Only environmental factors are important, as they define how well the child will be supported by the environment.
  - C. The health condition, personal factors, and the environment interact, so they all contribute to the individual's ability to function.
3. Child-centered treatment approaches are effective, because the intervention specialist can focus fully on the needs of each individual child. (T/F)

### ANSWERS:

**1. FALSE!** All children have the right to grow up in a family environment. It is well known that the institutionalized setting, even in the best case, does not provide the individualized care and interaction that a family environment can provide to the child and that children become increasingly delayed the longer they remain in residential institutions.

**2. C IS CORRECT.** All three factors influence how the child will develop.

**3. FALSE!** Parents know their children best. Today we know that interventions, particularly for young children, should be provided in the context of the family environment and take into account important routines. For example, it may be more important to the family that the child can come along on outings or daily shopping without major temper tantrums that cause comments or pity from the public than that the child learns to repeat a word or learns to stack blocks. It is therefore essential that the specialist works with the family as a team and listens carefully to the family's priorities.

In the past, a common approach was to consider newborns and young children with disabilities as different and defective. Some infants with disabilities were removed from their families, communities and society and placed into institutions, often away from the mainstream of society, where they remained for life. Other children were hidden by families away from public view in their homes to avoid stigma and discrimination.

While this still happens, it is, of course, no longer acceptable. Four main reasons are often cited to advocate for the full social inclusion of young children with disabilities or developmental difficulties:

### 1. Human Rights Rationale:

Children with disabilities and/or developmental difficulties are children first, with needs and inalienable rights. They are protected by the UN Convention of the Rights of the Child (UNCRC), ratified by all countries in the CEE/CIS region. For every single child, including every single child with developmental difficulties, governments are required to ensure:

- The right to life, survival and development
- Respect for the best interest of the child
- The right to non-discrimination; and
- The right to participation.

**As such, children with disabilities and/or developmental difficulties have the same rights of growing up in their families and communities, participating fully and on an equal basis in society, and receiving all the necessary services to thrive.**

Children with disabilities are also covered by the UN Convention on the Rights of People with Disabilities (UN CRPD) which defines “persons with disability to include those who have long-term physical, mental, intellectual or sensory impairment which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (UN CRPD, 2006). The CRPD has been signed by most countries in the CEE/CIS region.

Over the past decade, the programmatic approach to disability has also changed gradually. While children are still assessed and may receive a “diagnosis” (e.g., “Autism Spectrum Disorder”, “Down Syndrome”, “Hearing Impaired”...), emphasis is now placed on how the condition affects the child’s daily life and his/her ability to participate in society. Consequently a “diagnosis” now has acquired a new meaning: it is not a label; it is a term that alerts us to the fact that the child needs additional benefits and services. This approach is outlined in the International Classification of Functioning, Disability and Health (ICF) which looks at disability as the “the interaction between individuals with a health condition (e.g. cerebral palsy, Down syndrome and depression) and personal (way of learning, language understanding, literacy skills, interests, quality of attention etc.), and environmental factors (e.g. negative attitudes, inaccessible transportation and public buildings, and limited social supports)” (WHO, 2015).



All individuals have strengths and weaknesses in their functioning. It is not the individual who must overcome impairments or developmental difficulties to be allowed to participate in society, but it is the responsibility of society to remove barriers that make it difficult or impossible for some of its members to participate fully. Increasingly, communities are promoting social inclusion and see the benefits of creating a more caring and enriching environment for all, thus building social and economic capital.



The International Classification of Functioning, Disability and Health (ICF) puts the notions of ‘health’ and ‘disability’ in a new light. It acknowledges that every human being can experience a decrement in health and thereby experience some disability. This is not something that happens to only a minority of humanity. The ICF thus considers disability as part of the human experiences. The cause is less important to daily life and ability to function than the impact a particular condition has on daily functioning (WHO 2002).

## 2. Economic Rationale:

Research has shown that children growing up in an institution and or in the context of neglect, abuse, and violence, have an increased likelihood to experience significant developmental delays, chronic health and mental health problems and poor achievement. This results in reduced contributions to society and an increased costs in terms of services that are required for treatment, rehabilitation, and remediation. In the CEE/CIS region, young children with disabilities, particularly those with additional social disadvantage, are at greatest risk for growing up deprived of parental care in an institutional setting and/or to suffer from abuse and neglect (Sethi et al, 2014).

A good example of how expensive it is to not intervene early on but to rely on remedial services later on in life is illustrated by a recent UK study on the costs incurred by parental mental illness on the young child. This study has shown that the cost of services that need to be provided over the lifespan is about 25 times the cost of providing effective support early on in life (Bauer et al, 2015). Parental mental illness, such as perinatal maternal depression can result in developmental delays and mental conditions in the young child. You can find more about this topic in the module on Parental Wellbeing

Children with disabilities or developmental difficulties that receive support and early intervention are more likely to be able to function in their families and become productive and socially integrated adults. Aside from the many human rights violations that have been observed in institutional settings, institutional care is invariably more expensive to society than individuals that can manage their own care and live in protected group homes or independently.

## 3. Scientific rationale.

*"Most mommies and daddies tell me "I thought there was a problem at 14 or 15 months... and they told me let's wait and see because sometimes some kids grow out of it.' Well, that's not a good answer. We've got to make the distinction between less important problems, where we can wait and see from core problems, which involve a lack of reciprocity and a lack of getting to know your world. For these core problems, we have to act on it yesterday. We can't wait nine months, we can't wait two months."*

(Stanley I. Greenspan, M.D., Child Psychiatrist in <http://www.firstsigns.org/concerns/flags.htm>).

### To wait or to intervene?

This is often one of the most challenging questions for home visitors. You may be reluctant to refer a child for a formal assessment, because you are worried that this child and family will be labeled and stigmatized. However we know that the early days are just as critical for children with developmental difficulties. Despite this, many young children with developmental difficulties never access the early intervention services that would be so beneficial.

Because of a relatively large variability in achieving developmental milestones, families and professionals do not always feel an urgency to obtain a formal assessment (e.g., one child may have a large receptive and expressive vocabulary at age 12 months while another child with limited speech at that age starts speaking in sentences at 24 months). Often, professionals and parents hope or expect that the child is just "a late bloomer" and will catch up. Also, many countries do not yet have policies for actively monitoring young child development. They may lack agreed-upon screening policies and valid, standardized assessment tools that health and early education professionals are trained to use, and guidance of when a child's development should be assessed.



Even in countries that have been using developmental monitoring and screening for some time (e.g., UK, U.S.), some children are not identified, assessed and diagnosed until age four years or even later. For example, it has been reported that parents often identified some symptoms or red flags of Autism Spectrum Disorder before two years of age, but the child was not diagnosed until age four when delays and behavior patterns had become more entrenched and valuable time for early intervention services had been lost (Hyman 2014). Sometimes these parents thought that their child had a hearing problem or language delay, or was just not very social, but when mentioning their concerns, they were told to wait and see.

The brain develops most rapidly up to age 5 (*see also the module on Early Childhood*) and is very plastic. Therefore, it can easily be affected by proper intervention. Often medical professionals wait until the age of 5 years to give any kind of specific diagnosis. The child is labeled as a child with a “Developmental Delay or Disorder”, immediately referred to Early Intervention, and monitored. Often, when young children are identified at the earliest age and receive proper and intense Early Intervention services, the child may not need a diagnosis at age 5. Standardized developmental screening tools can be used to track and monitor the advancement of the intervention (*see module on Developmental Monitoring and Screening*).

In the case you decide to wait before referring a child for assessment, you may consider several actions to ensure that valuable time is not lost for a particular child, including:

- Discuss your concerns with the parents and give them tips and materials on how to promote certain areas of development
- Schedule an early next visit in agreement with the parents to see with the parents how the child is doing
- Ask parents how they would prefer to proceed. If a family is anxious and services are available, they may be reassured by additional professional advice.

#### 4. Programmatic Rationale

Intervention programs can significantly improve the overall rate of development of the child and also reduce certain behaviors that may make it more difficult for the child’s acceptance in society. For example, there are a number of evidence-based intervention models and techniques for ASD that reduce symptoms of autism, and improve language and social behaviors (Hyman 2014).

Programs that address the child within the context of the family and everyday routines and engage family members – parents, siblings, grandparents – as partners in the early intervention approach are often the most successful in promoting development.

In order to work well with families, it is important to be clear on the definitions below. The module on Developmental Monitoring, Screening will provide you with more detail on how to monitor, identify and refer children for additional services they might need.

**Definitions.** Please see the module on Developmental Monitoring, Screening, and assessment for more detail on this topic.

**Developmental monitoring.** “A child’s growth and development are followed or monitored through a partnership between parents and health care professionals...” Monitoring healthy development means not only paying attention to symptoms related to a child’s condition, but also to the child’s physical, mental, social, and emotional well-being. <http://www.cdc.gov/ncbddd/childdevelopment/facts.html>

At each contact (for example, with you, the home visitor, or with the child’s doctor, the health professional looks for developmental delays or problems and talks with the parents about any concerns they might have with respect to the child’s development.

**Developmental screening.** A short checklist or test may be used to see if the child is learning the expected basic skills at the approximate age, or if they might have delays. Some countries, like the United States or the UK, screen all children with the same tool at specific ages (e.g., the UK uses developmental screening at birth, 14 days, 6-8th week of life, 12 months, and 24-30 months).

**Developmental assessment.** When delays are noted, a structured assessment may be conducted by a developmental assessment specialist, or if possible, by a team of professionals tailored to the child's particular developmental difficulties (e.g., pediatrician, language specialist, audiologist, occupational therapist, child psychologist, physical therapist, infant mental health specialist). The family should be a partner in this process.



### Reflection and discussion

Here are some questions for reflection:

Why is it so important to work with the whole family? How can this affect outcomes for the child with developmental difficulties?

### ANSWER:

The family spends the most time with the child with developmental difficulties. Learning and intervention strategies suggested by the specialists are effective when they are incorporated into daily routines and become part of family life. Also, the learning goals for the child should be connected to everyday life, and social participation and inclusion. Do you think one can create such an environment for a young child outside the home context, say in a health clinic?





## YOUR ROLE IN PREVENTION OF DISABILITIES AND DEVELOPMENTAL DELAYS



There are many medical, congenital and environmental conditions that affect child development. If you are curious to learn more about a certain condition and learn about available resources and organizations, see <http://www.cafamily.org.uk/medical-information/conditions/>



### Self-assessment

The following table lists some common conditions. Think of how you in your role as a health visitor can contribute to the prevention or the betterment of the life of a child with a disability or at risk of a disability of disabilities. **Keep in mind that parents generally want to do what is best for their unborn or young child, and this strong motivation can be maximized for the prevention of disabilities and developmental difficulties.**

Conditions	Causal factors	What you can do
<b>What you can do during the pregnancy:</b>		
Low birth weight and very low birth weight	Poor nutrition, maternal smoking	
Fetal alcohol syndrome	Alcohol use during pregnancy	
Anencephaly, hydrocephalus	Lack of folic acid before pregnancy and in the early weeks	
<b>What you can do after birth:</b>		
Prematurity, LBW		
PKU	Metabolic disorder	
Congenital conditions	Different causes during pregnancy or delivery	
<b>What you can do in early years</b>		
Failure to thrive, Stunting	Poor nutrition, lack of stimulation	
Disabilities and Developmental delays	Maternal depression, parental mental illness, intra-family violence, disability, neglect, congenital conditions, prenatal conditions, injuries, low birth weight, unknown causes	

Look/Click on the following table and compare your answers with our suggestions

Conditions	Causal factors	Examples of what you can do in your role as home visitor
<b>What you can do during the pregnancy:</b>		
Low birth weight and very low birth weight	Poor nutrition, maternal smoking	Advise pregnant women on healthy life styles, including nutrition, smoking, exposure to smoking, insufficient rests, untreated medical conditions and infections....
Fetal alcohol syndrome	Alcohol use during pregnancy	Counsel on no use of alcohol during pregnancy
Anencephaly, hydrocephalus	Lack of folic acid before pregnancy and in the early weeks	Promote use of folic acid in all young women, women wanting to get pregnant, and during the early weeks of pregnancy
<b>What you can do after birth:</b>		
Prematurity, LBW	See above and other causes	Promote breastfeeding and skin-to-skin contact, support bonding and attachment processes, monitor the child's development, link family to additional services as needed, early stimulation/enrichment programs
PKU	Metabolic disorder	Help the family comply with the special diet prescribed for the child
Congenital conditions	Number of causes	Promote breastfeeding and skin-to-skin contact, support bonding and attachment processes, monitor the child's development, link family to services as needed
<b>What you can do in early years</b>		
Failure to thrive, Stunting	Poor nutrition, lack of stimulation, perinatal depressions	Promote breastfeeding, good nutrition, responsive and nurturing care, stimulating environment

Conditions	Causal factors	Examples of what you can do in your role as home visitor
<p>Disabilities and Developmental delays</p>	<p>Maternal depression, parental mental illness, intra-family violence, disability, neglect, congenital conditions, prenatal conditions, injuries, low birth weight, unknown causes</p>	<ul style="list-style-type: none"> <li>• Propose age and development-appropriate activities to stimulate the child’s development</li> <li>• Focus on daily routines and functioning needs of the child</li> <li>• Monitor the child’s milestones, and</li> <li>• Always help the family to enjoy the child and support parent-child attachment</li> </ul> <p>Also: use screener for maternal depression; provide counseling and listening support; refer and assist family to get access to appropriate early intervention services; promote social inclusion</p> <p>Same as above and signpost family to specialty services, as needed</p>



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## VI

## YOUR ROLE IN SUPPORTING FAMILIES WITH CHILDREN WITH DISABILITIES AND DEVELOPMENTAL DELAYS – COMMON ISSUES

*Parents who responded to (our) survey described feelings of isolation; struggling to come to terms with the news of a child's disability; a lack of time for themselves and each other; problems balancing work and caring; increased financial worries; a lack of support and understanding from professionals and the wider family network; a lack of suitable services and having to fight for those that are available*

(Contact a Family, 2013, based on a survey of more than 2000 parents).

As the trusted professional who sees the family on a regular basis, you provide both information and support. To provide good information on the services that are available to families in your community, nationally or virtually on the internet, it is good to map what is available to you and your families, and know how you can help your families open doors to the additional services they need. You can find more about this topic in the *module on "Working with other Sectors"*. In addition to information, families also will benefit from other types of support from you.



Below find two **video clips** that talk about what families experience from the family and professional perspective:

An Encounter of a Different Kind (Croatia) (to be obtained from Croatia) and <http://www.opensocietyfoundations.org/multimedia/early-childhood-intervention-power-family>

In this section, we will raise some of the common issues you may encounter when working with families that have a child with disabilities or developmental difficulties. As explained in a recent UNICEF Croatia (2014) report on supporting parents of children with disabilities through parenting groups, parents of children that develop typically do not usually think about possible bad outcomes. They address problems as they are encountered. The parent of a child with developmental risk or disability often acquires an additional "plus" fear in the present, as well as a fear for the future of their child.

### A. Parenting a child with disabilities or developmental difficulties

Parents who raise children with disabilities go through their parenting under more difficult conditions than parents of typically developing children. These conditions are a result of the additional care that is required for their child, such as frequent visits to specialists, more frequent hospitalizations and medical examinations, and more demanding daily care. Also, parents have a greater need for information and they are continuously dealing with the fact that the child is different and the future is less certain. Every parenting experience is different. It can be described as a journey with a lot of challenges.

As the child is growing up, parenting is changing or growing up, too. Some have tried to describe this journey as a path consisting of different stages of adaptation to a new life conditions. This may happen in **four stages in a process of adaptation** (Miller, 1997). These stages may follow each other; they can also overlap, and parents may return to earlier stages. It is a dynamic process and a stage is never be "completely conquered". The support provided to these parents can contribute significantly to the psychosocial stability of family life, help them participate more actively in society, and can help them in creating a more stimulating environment for their child. When visiting these families, *it is important for you to be aware that parents will go through these stages and give them your understanding and support.*

**The first stage** begins when a parent realizes that a child's developmental outcome is at-risk, i.e., that the child has a disability or a developmental difficulty. This stage is characterized by parents needing to **"survive"**. This moment of realization is often etched deeply into the memory of parents. The entire first stage of adaptation is characterized by strong feelings of helplessness and loss of control over their own lives. Parents go through the process of "surviving" in their own individual way, so the duration of this period is also determined individually. However, this process is easier when parents have access to information that their feelings are a natural and healthy reaction to what has happened. What home visitor can do is to remind parents gently that they also have to take care of themselves. There is a very strong tendency of parents to completely ignore themselves and their needs and those of other family members and to subordinate everything to what they think might be the needs of their child.

**The second stage** starts when a parent realizes and accepts that life will be different than planned. The focus of this stage is **"searching"** in two main ways. "Outer searching" begins with looking for the child's diagnosis and interventions. In this phase, parents become very active in seeking help. If they are left to themselves, this period can be very exhausting for them, both financially and mentally. Using your professional experience and what you have learned in the module "Working with other sectors" can help you in supporting families during this phase in finding an easier and shorter way to developmental assessment, services, and support.

Parents' "inner searching" may be marked by such questions as: "What does the child's disability mean for my life and my relationships with others. What does it mean for my other children?" Thus begins the search for a new identity that will include parenting a child with a disability. This is a difficult period because in their inner searching, parents ask themselves a number of questions that often they cannot answer immediately. They can become depressed and anxious, as well as feel a sense of incompetence in their parenting role.

In their searching and struggle to find answers, many parents go through a process of tremendous personal growth. Gradually, they manage to integrate their inner and outer searching. Such parents may become catalysts of change for advancing the social care of children with disabilities. They have discovered that, to some questions, there are no simple answers that life has many layers, and that unpredictability is a part of life. They may also discover that the continuous progress in science and technology creates new opportunities for the future of their children. Searching never stops completely and continuously adds new dimensions to parental insights, and gives the parents themselves new energy and hope.

**The third stage** reached in this process of adaptation is called **"settling in"**. Outer searching for various forms of help has subsided, the pace of family life has stabilized, and the child may be participating in a support program, nursery or school. During this phase, parents learn that they have gained new skills and new insights and that they understand many things in a new way. They feel more confident and assertive and know the ways of addressing and solving problems.

**The fourth stage** involves **"separating"**. Separation is a normal process that does not happen at once. It begins at birth and occurs each day in small increments. In the case of children with disabilities, this process can be altered and slowed down. Parents are exposed to special efforts to help their children become independent and enable them to take care of themselves. Separating is often filled with the same emotions that the parents experienced during the phase of dealing with the child's disability. Making a decision about separation includes an enhanced inner and outer search of what was done or omitted. The end result, as shown by the research and experience of N. Miller, is the new "settling in" and connection with the life of their child in a new way.

Home visitors play an important role in supporting parents because they can support the process of parental coping with the fact that their child is different. The empowerment of parents develops self-esteem and problem-solving skills. However, empowerment is possible only if trust and a partnership has been established between parents and home visitors. A partnership approach to parents means that parents are involved in making decisions and that their point of view is valued and appreciated, because they are the experts who know their child the best.

**B. Feelings of parents and family members**

The relationships among family members will make a tremendous difference in how family members and the family as a whole is able to cope with the additional demands of raising a child with disabilities or developmental difficulties. These relationships are also likely to change over time. As a trusted professional you may be able to observe or family members may share with you when extra support is needed.

**Some common responses of families are listed:**

<p><b>The feelings of parent/s</b> - Grief, guilt, and blaming.</p>	<p><b>What you can do:</b></p>
<p>When a child is born with a genetic condition or very prematurely, parents and families may go through a grieving process. The anticipated, joyful event of the birth of a healthy child has not happened. In addition, the newborn or young child may require extensive medical support and individualized attention, and strain the family’s physical energies to cope and their financial resources. Self-blame or blaming the partner for the cause, depression, and loss of hope may make it difficult for the parents and family to meet the challenges of dealing with the child’s problems and forming a secure attachment. Some families cope by focusing their energies on the child; they may push and even force progress in development, sometimes at the cost of other children in the family or the other parent.</p>	<p>Families have many different ways of dealing with this situation.</p> <ul style="list-style-type: none"> <li>• Understand that parents may be grieving the loss of the “healthy child” that was never born and may need some time to adjust.</li> <li>• Be available to listen, acknowledge the family’s feelings and show your support.</li> <li>• Link the families with resources, including other families, and parent support groups.</li> <li>• Help the family focus on the child’s strengths and potential, find enjoyment in interacting and playing, and help the family celebrate the successes and achievements of their child’s development.</li> <li>• Provide accurate information.</li> <li>• Link the family to services, and if needed, help the family open doors.</li> <li>• Be a good role model in your own interactions with all family members.</li> <li>• Advocate for the services that your families require.</li> </ul>



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The feelings of siblings.	What you can do:
<p>Family life often centers around the needs of the child with disabilities or developmental difficulties. The following issues are often experienced by siblings of children with developmental difficulties (Contact a Family 2013)</p> <ul style="list-style-type: none"> <li>• Limited time and attention from the parent/s.</li> <li>• Need to participate in the day-to-day care of their sibling.</li> <li>• Feeling of guilt (guilt for not being handicapped, feeling guilty about being angry with the sibling or jealous for attention received, making it up to the parents by being perfect...).</li> <li>• Worry about bringing friends home.</li> <li>• Stressful situations at home.</li> <li>• Restrictions on family activities at home and in public.</li> <li>• Feeling embarrassed about the sibling in public.</li> <li>• Being teased or bullied about the sibling.</li> <li>• Feeling very protective of the sibling.</li> <li>• Worrying about the future and own long-term responsibilities.</li> </ul>	<p>What you can do.</p> <ul style="list-style-type: none"> <li>• Take into account the wellbeing and needs of whole family during your visits and interactions.</li> <li>• Share with parents some of the common issues siblings may have with living with a brother or sister with developmental difficulties.</li> <li>• Understand that the feelings of siblings are not constant, but change over time and with each child's development.</li> <li>• Role model positive and honest interactions with the siblings.</li> <li>• Invite siblings to participate during visits and speak their mind.</li> <li>• Include siblings in activities for families, but recognize their right to non-participation.</li> <li>• Link older siblings to resources on the internet.</li> </ul>

Getting the child assessed and diagnosed.	What you can do:
<p>There are thousands of conditions, many very rare. This means that some children are never diagnosed or only diagnosed after a long journey of visits to many different professionals. Early intervention should start before a diagnosis is made, and children and families need support right after it has been determined that there is some risk to development. Families can respond differently to being able to obtain a definitive diagnosis. Some families spend time, energy, and resources in searching for the cause, while other families prefer to focus on dealing with the child's immediate challenges.</p>	<ul style="list-style-type: none"> <li>• Help families who are searching for a diagnosis by referring them for formal assessments.</li> <li>• Help families understand that a diagnosis may not predict how a child will develop, since development may depend on the interplay of the condition, the family, and the support provided by the environment.</li> <li>• Know your referral sites and the organizations and professionals involved in assessment and early intervention.</li> <li>• Be aware of other sources of information that might be useful to the family.</li> <li>• Remember that the family may also be vulnerable to individuals who give false promises and hope.</li> <li>• Provide sufficient time and space for listening to families with empathy.</li> </ul>

Family isolation and loneliness.	What you can do:
<p>Families may become absorbed in their child’s problem and the challenges of making it from day-to-day. Families often find it helpful to get in touch with other families facing similar problems and find that such families more truly understand what they are going through and are good sources of support. In the very early phases, parents may not be ready to connect with others. Give them time. Do not assume that because they have refused once, they are unwilling to consider this option later on.</p>	<ul style="list-style-type: none"> <li>• Know family support groups and associations in your area (and country)</li> <li>• Exchange information with your colleagues on families that are willing to reach out to others in similar situations</li> <li>• Be aware of parent and family support groups that operate website support for certain disabilities or issues and assist families interested in making such contacts</li> <li>• Support families in creating a support group</li> </ul>



**Additional resources**

Below you can find two websites that list many common and rare conditions. For each of the conditions, you can also find additional websites for more detailed information, parent associations, and multi-media resources.

<http://www.cdc.gov/ncbddd/socialmedia/index.html>

<http://www.cafamily.org.uk/medical-information/conditions/>

*The UK organization Contact a Family has produced a series of easy-to read booklets for families that can be useful in your work. For example:*

*Relationships and caring for a disabled child*

[http://www.cafamily.org.uk/media/669849/relationshipscurrent\\_updated\\_may\\_2013.pdf](http://www.cafamily.org.uk/media/669849/relationshipscurrent_updated_may_2013.pdf)

*About living without a diagnosis*

[http://www.cafamily.org.uk/media/737817/about\\_diagnosis\\_living\\_without\\_a\\_diagnosis\\_24\\_july\\_2014\\_kb.pdf](http://www.cafamily.org.uk/media/737817/about_diagnosis_living_without_a_diagnosis_24_july_2014_kb.pdf)

*On siblings*

[http://www.cafamily.org.uk/media/629582/siblingscurrentlastupdatedjan13\\_low\\_res\\_for\\_web.pdf](http://www.cafamily.org.uk/media/629582/siblingscurrentlastupdatedjan13_low_res_for_web.pdf)

## VII

## NEW CONCEPTS IN WORKING WITH FAMILIES

There are new approaches with particular potential to support your families, and you may be able to promote these in your area or health center or integrate some of the concepts in your work and in collaboration with other sectors. Two approaches are particularly worthwhile for our reflection and consideration:

### A. Routines-based approach

In the past, the intervention specialist often worked alone with the child on certain skills prioritized by the specialist. However, families often need support with daily routines, such as having the child be able to express the need of going to the bathroom or ask for a drink or control tantrums or stereotypical behaviors in public places. With the routines-based approach, the specialist comes to the family's home or accompanies the family on outings to work with the family and child on their priority behaviors in the natural environment. The three video links below explain this approach further.



#### Video clips

<https://www.youtube.com/watch?v=OpxGC6G0HMY>

This is the first in a three part series of short videos featuring three current early intervention service providers sharing their insights into providing supports and services using a routines-based approach. Part 1 features an experienced interventionist sharing her personal journey from a clinical approach to one focusing on family routines and activities as the context for effective early intervention.

[https://www.youtube.com/watch?v=sL\\_WOCu3Ptg](https://www.youtube.com/watch?v=sL_WOCu3Ptg)

Part 2 features three early interventionists discussing and demonstrating what intervention looks like when it is provided by collaborating with families during their natural routines and activities.

<https://www.youtube.com/watch?v=jA6lOf9A298>

Part 3 features three early interventionists sharing their insights about how they evolved their practices towards a more effective, routines-based intervention approach. As a home visitor, you have not been trained in early intervention, but it is important to understand the importance of routine-based approach.

### B. Team around the Child (TAC)

To overcome the fragmentation on often confusing and overwhelming number of services offered to children with developmental difficulties and their families, TAC builds service provision on the following principles :

- *The child is treated as a whole child and all developmental areas are stimulated together*
- *The family is supported and treated as a whole family*
- *Parents are equal members of the TAC/intervention team*
- *Education and therapy are joined together into a whole approach*
- *There is a single multiagency action plan to support child and family*

For example, if the speech is impaired, social skills will be affected and cognitive skills will be lagging since the child cannot express herself and learn. So, a speech therapist needs to work on all 3 developmental areas or several team members have to work together.



To read more about this approach, see <http://www.teamaroundthechild.com/allnews/developmentsintreatment/1406-tac-for-the-21st-century-a-unifying-theory-about-children-who-have-a-multifaceted-condition-an-essay-by-peter-limbrick.html>



### Reflection and discussion

1. How can your suggestions to parents on encouraging the early development of their child encompass a routine-based approach?
2. Read the description of the three cases below. In your role as home visitor, how can you support each of these families? What other services or organizations could you involve in supporting these families?



### Case study 1

When meeting this young teenage mother, you see that she is alone in her room. Her baby, four weeks old, was born one month premature and was just released from the hospital two days ago. The grandmother has taken off from work to help her daughter and has been caring for the baby, but she will need to get back to work soon. The mother's boyfriend lives in the same building, but you hear that he is afraid of tiny babies



### Case study 2

When meeting a new family, the mother shared the following story with you: She and her children suffered from daily verbal abuse by her husband. She decided to leave her husband and divorce him after he physically abused and her two year-old son. Before the abuse by his father, Francis spoke little and after the divorce he stopped talking. He became aggressive towards his mother, sister, and grandmother, if he did not get what he wanted.



### Case study 3

The mother of a 13-month-old son shares this story with you.

After a normal pregnancy and childbirth and wonderful first few months, our problems began and have not stopped. Our son did not grow; he could not keep his head up and was very limp. It disturbed me greatly and I was very concerned. When he was three months old, the pediatrician, at our insistence referred us to a pediatric neurologist who gave us a diagnosis.

We went to physiotherapy, and got some training. My husband and I take turns in working with our son, and we have engaged a private physiotherapist. All we were told is that it depends on us how our child will develop. Our own parents have also offered their advice and are reproaching us. We began to feel more and more guilty and disagree more and more what we should do. But we never neglected our son's exercises. We have also drifted apart from our friends to avoid the uncomfortable questions and tips that they feel they need to provide us with.

Additionally, it scares me, but I think that our child is not even interested in what is happening around him. We are so dedicated to his exercise, but he is barely crawling and not recovering. I keep wondering what

we did wrong. When we go somewhere, we always carry him so that no one notices that he still is not even standing. When I see other parents who do not bother about their children who are progressing nicely, I get angry and jealous.

### SUGGESTIONS FOR DISCUSSION:

Case 1: In this case, you may want to focus on prevention and risk reduction:

- Assess risk (premature baby, young and unmarried young mother...)
- Identify opportunities (grandmother working, but willing to help; young father in the same building; your first visit is soon after discharge, so you can provide needed support)
- Review relevant information (modules on attachment and how to promote it, ways of engaging fathers, monitoring of child development...)
- Plan for providing enhanced services to reduce risk

Cases 2 and 3. These families have substantial needs that you will not be able to meet on your own.

- The whole family unit needs to be addressed. Addressing the wellbeing of the other family members will be essential to go along with intervention services for the child.
- In both cases, you will need to work with other services (see module on working with other sectors) and ensure that these families receive intense services. In case 2, mental health support may be needed for all family members. In case 3, as a team, the level of intensity of the exercises undertaken by the parents alone may need to be reevaluated. How intense do they need to be? Are there other individuals who could conduct these exercises? What attention should be given to the parents' wellbeing? Would they benefit from meeting with other families?



As we mentioned earlier on, these families need your special support and empathy. When you finish your home visit, you can close their door. They, on the other hand may live a life that was very different from what they expected. You can contribute to their resilience and wellbeing.

To complete this unit, make sure you review the module on developmental monitoring and screening.



## ANNEX



## INFORMATION CARD 1: FAMOUS INDIVIDUALS

**Famous individuals**

<http://www.iidc.indiana.edu/cedir/kidsweb/famous.html>

<http://hcdg.org/famous.htm>

[http://www.huffingtonpost.com/2013/10/22/famous-people-with-disabilities\\_n\\_4142930.html](http://www.huffingtonpost.com/2013/10/22/famous-people-with-disabilities_n_4142930.html)

**Chris Burke**

Chris Burke, best known for the character, Corky, played for four years on the television series, *Life Goes On*, and became one of America's favorite personalities. Through his work, he was able to transform America's image of the people with disabilities. Ever since Chris spoke his first word, it became clear that he was a remarkable individual with many talents.

Chris Burke was the first person with Down syndrome to star in a weekly television series. Currently, he serves as the National Down Syndrome Society (NDSS) Ambassador. Chris had the faith in his own abilities and the courage to face prejudice as he pursued his dream to become an actor.

Today Chris travels all around the country delivering inspirational speeches to various groups of children, students, parents, and professionals. He not only serves as editor-in-chief of the NDSS magazine for teens and young adults with Down syndrome, but also writes a column and responds to readers' correspondence in a regular question and answer feature in the magazine.

**Geri Jewell**

Geri Jewell is an actor and comedian born with cerebral palsy. She is most famous for her roles on *The Facts of Life* and HBO's *Deadwood*. Geri was awarded a National Rehabilitation Hospital Victory Award in 2006 and also works as a motivational speaker. Visit her website at [www.gerijewell.com](http://www.gerijewell.com).

**Itzhak Perlman**

Perlman began his music career at the Academy of Music in Tel-Aviv, Israel. In 1958, at the age of 13, Itzhak Perlman won an Israeli talent competition. This win made it possible for Perlman to travel to the United States to tour and appear on television. He then stayed in the U.S. and continued his musical training at the Juilliard School in New York City.

In 1964, Perlman won a contest among young musicians known as the Leventritt Competition. Winning this competition opened the door for young Perlman to perform his violin music all over the world.... Itzhak, now an acclaimed violinist of his generation, has performed with every major orchestra and in recitals and festivals the world over.

Born (1945) in Tel Aviv, Israel, Itzhak Perlman contracted polio at age 4, permanently paralyzing his legs. He performs his music while seated and walks with crutches. Itzhak is a well-known advocate for people with disabilities, actively promoting laws to ease access to buildings and transportation.



### **Stephen Hawking**

Stephen Hawking knew what he wanted to do by the time he was eight years old. He did not want to study medicine, a career his parents hoped he would follow. Instead, Hawking decided to be a scientist and chose physics. Stephen was interested in studying the universe.

He attended Oxford University in England, as an undergraduate student. He received his Ph.D in 1966 from Cambridge University. By the time he was 35 years old, Hawking was Cambridge's first Gravitational Physics professor and received the Lucasian Professor of Mathematics award.

Stephen Hawking has also published a book called *A Brief History of Time: From the Big Bang to Black Holes*. The book tries to explain many of Hawking's physical and mathematical ideas and calculations without using math. The book became a best seller and was made into a movie.

When Stephen Hawking was 21-years-old, he was diagnosed with amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease. This disease attacks the nerves that control a body's voluntary movements. It affects walking, speaking, breathing, swallowing, etc. At the time of his diagnosis, the doctors gave Hawking two years to live. Hawking has defied this time frame and is still working. Today, Stephen cannot move much at all, has trouble holding his head up, and cannot speak, though he doesn't let it stop him. He now uses a special computer that displays the text he types and speaks what he types with an electronic voice.



### **Stevie Wonder**

One of the most beloved singers alive today, Stevie Wonder is a musician, singer and songwriter who was born blind. He was born six weeks early. The blood vessels at the back of his eyes had not yet reached the front and aborted their growth, hence his blindness.

Considered a child prodigy, Stevie signed with his first record label at age 11, Motown's Tamla label, and he's been performing since. Over his wildly successful music career, Stevie has recorded more than 30 U.S. top ten hits, including his singles "Superstition," "Sir Duke" and "I Just Called to Say I Love You."



## INFORMATION CARD 2: WEBSITES ON DISABILITIES AND SPECIFIC CONDITIONS

To support families that have special needs, you will find that the Internet provides a wealth of information. Websites can link families to information about a condition, possible interventions, services, tools, as well as emotional support and even friendship. It is, of course particularly important to use reputable sites, and not those that might provide false hopes or misinformation.

**General Websites.** These websites can lead you to additional websites for information and resources for specific conditions.

UK: <http://www.cafamily.org.uk/medical-information/conditions/>

### **Websites for specific conditions:**

Fetal Alcohol Spectrum Disorder: <http://www.fasdtrust.co.uk/cp1.php>

Autism Spectrum Disorders – Resources for Bosnian, Russian, Serbian, Romanian...:

<http://www.autismspeaks.org/family-services/non-english-resources>

<http://www.firstsigns.org/concerns/flags.htm>

This site is a social networking site for parents, with a particular focus on autism.

<http://www.theparent.net/index.asp>

Birth defects and developmental disabilities:

<http://www.cdc.gov/ncbddd/socialmedia/index.html>

### **Websites about and for siblings**

Sibs is the only UK charity representing the needs of siblings of disabled people. Siblings have a lifelong need for information, they often experience social and emotional isolation, and have to cope with difficult situations. [www.sibs.org.uk](http://www.sibs.org.uk)

<http://www.siblingsupport.org/about/about-the-sibling-support-project>





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