

MODULE 13

**DEVELOPMENTAL
MONITORING
AND SCREENING**



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KEY MESSAGES - why is this topic important for you?

- Depending on the communities where you work, 1-2 of every 10 children on your caseload may be at risk of experiencing a disability and/or a developmental difficulty.
- Early identification of infants and young children with disabilities and/or developmental difficulties is critical. The earlier these children are identified, the sooner they can receive the services they need to support their development. This, in turn, will make it more likely that these children will grow, thrive, and achieve their potentials in full social inclusion.
- Keep in mind that developmental difficulties can also be caused by the environment (for example, by a depressed caregiver, intra-family violence, child maltreatment, death in the family, severe poverty, etc.)
- Sometimes families know already that their child is not developing in the same way as many other children of the same age. In other cases, families may not have realized that their child is experiencing difficulties. Either way, as the professional closest to the family and drawing on your training in child development and professional experience, you need discuss this important topic with the family.
- You have a key role to help the family gain an understanding of the situation, link them with formal assessment and early intervention services, advocate for them with the relevant support agencies, be there for them with supportive listening and advice on ways of dealing with stress, and most importantly, foster continued parental attunement and nurturing interactions between the parents and their child.
- To effectively support your families, you need to develop the skills to monitor the development of young children during your visits. If customary, you may also periodically use a developmental screening tool with the participation of the parents.
- To help families understand what is involved in screening and assessment, you should be familiar with these processes.
- Discussing with parents and families that their child may need to be formally assessed for a delay can be a sensitive topic and will require your professional communication skills and empathy to provide the support these families may need.
- Your role with the child and family does not end when a child is receiving early intervention services. The family will continue to need your support, and you are an essential and valuable member of the professional “team around the child” and the family.
- Finally, don’t forget to also help families celebrate successes and achievements and help families to remain hopeful and enjoy their child.



LEARNING OUTCOMES

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

- An understanding of what is involved in developmental monitoring, screening and assessment.
- Understand the concept of milestones and monitoring tools.
- Be able to explain to your families of what is involved in periodic screening and in a full assessment.
- Provide basic advice and support on how a family can promote the development of their child with developmental difficulties.
- Understand your continued role with the family and child when a child is receiving early intervention services.

INTRODUCTION

I



Self-assessment – True/False Statements

Give true/false answers to the following questions:

1. In developmental monitoring, you take an assessment tool and test the child to see if he/she is able to perform behaviors expected for this particular age group.
2. Parents tend to worry a lot about the development of their children. You will need to listen to their concerns, but rely on your own professional judgment to see if the child is delayed or not.
3. Developmental assessments are conducted by specially qualified professionals. However, home visitors can and should contribute to the assessment process.
4. The terms “development” and “growth” have the same meaning.
5. Emotional regulation in the child does not depend on help provided by parents.
6. If you are not sure if the child is experiencing developmental difficulties, the best strategy is wait and see.

ANSWERS:

1. FALSE. Developmental monitoring follows the development of the child over time, generally in discussion with the parents. A tool with developmental milestones may be used as a guide.

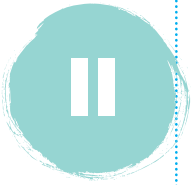
2. FALSE. Parents know their children best and are often aware that their child is experiencing some difficulties. Parent concerns are therefore an important component contributing to your professional opinion.

3. TRUE. Using formal assessment tools in a standardized (consistent) way requires training. However, home visitors may have important information based on developmental monitoring over time, the child and family’s unique situation, and the risk and protective factors influencing the child’s development.

4. FALSE. Growth generally refers to the physical growth of the child, while development encompasses multiple domains, i.e., physical growth, motor, language, social-emotional and cognitive development, and self-regulation/executive function.

5. FALSE. Infants learn to self-regulate with the help of responsive and nurturing parents.

6. FALSE. It is never a good idea to wait and let valuable time for development pass based on the hope that the child will be able to catch up. At minimum, if you have mild concerns, you may want to schedule an extra visit soon to provide further guidance to parents on how to stimulate their child’s development. If you are moderately or seriously concerned, you should refer the child as soon as possible for assessment so that intervention services can be planned as quickly as possible. Also, keep in mind that there are often significant waiting periods and delays for accessing assessment services, as well as early intervention services.



WHY DEVELOPMENTAL MONITORING IS SO IMPORTANT?

Young children develop most rapidly during the early years, but we are well aware that they develop at different rates. One child may have a large vocabulary at age one year, while another child only communicates with gestures, but starts speaking suddenly in sentences at age two. Some children may start walking at 10-11 months, when many age mates are moving around crawling.

Sometimes a disability or developmental difficulties are obvious. Ensuring that in such cases young children are formally assessed and receive intervention support at the earliest age is an important function of your work as a home visitor. It is one of the important ways to safeguard the wellbeing and social inclusion of children that develop differently.

In other cases, you may not be sure whether what you are observing or hearing from parents constitutes an early sign of a developmental difficulty. But, you will be visiting the family again, and if you are not sure you may want to schedule the next visit at an earlier time. Unlike clinic visits for illnesses or well-child services (e.g., growth monitoring, immunizations) where time is limited, doctors are rushed, and children are not in their natural environment, you can take the time in the child's home to observe interactions between the caregiver and the child and listen to the parents' accounts of developmental achievements and concerns. You may be the first to note that there are some developmental delays, and/or behavioral or social-emotional difficulties.



Home visits present a unique opportunity for you as a home visitor to observe, promote and monitor child development in a way that takes into account the special circumstances and needs of the child and the family.



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SOME DEFINITIONS

Definitions

- **Developmental Monitoring.** This is an ongoing activity from visit to visit, following how the child is progressing overall and in specific domains of development, i.e., gross and fine motor, cognition, language, social emotional, self-help skills, and self-regulation. Milestones, in the form of a checklist, may give the home visitor a tool to see when development appears to diverge from the majority of children.
- **Developmental Milestones** are functional skills or age specific tasks that a child displays for the first time. Skills, such as smiling at the parent for the first time, taking a first step, and saying “da-da” for the first time are called developmental milestones. Children develop at their own rate. As a result, it can be difficult to predict when a child will show a new skill. However, developmental milestones give a general idea of where the child is with respect to age mates, and what behaviors and skills may emerge next. Developmental and behavioral screening, using milestones, play an important role in early detection of developmental difficulties or delays and can lead to obtaining additional support and interventions to help children with their development.
- **Developmental Screening.** This can be a one-time or repeated activity at specific ages using a standardized, valid, and reliable developmental and/or behavioral screening tool. Screening tools are formal research-based instruments with questions about various domains of development (gross and fine motor, language, cognitive, social, emotional, daily functioning and self-regulation skills). Screening tools do not provide a diagnosis, but indicate whether children are developing well or whether there are concerns that should be followed up with a formal assessment. Some countries screen at specific ages (United States: 9, 18, and 30-36 months, UK: newborn, 1-2 weeks, 6-8 weeks, 12 months, and 24-30 months), and the information may be used to improve programming for certain groups or geographic regions and or, at age 2 ½ - 3 years, to see if young children are ready for preschool.
- **Developmental Assessment or Evaluation.** This is a comprehensive assessment of the child with the purpose of identifying strengths and weaknesses in terms of particular areas of functioning, often with the purpose of making a diagnosis and developing and planning the most appropriate early intervention support to promote optimal development.

IV

MONITORING DEVELOPMENT DURING HOME VISITS



Below, you will find a link to a **video clip** that describes what developmental monitoring may look like.

Between birth and 2 years, a child experiences important stages of growth and development. This video highlights normal development stages, providing advice when you, the home visitor, and the parents may be concerned.

<https://www.youtube.com/watch?v=SBFnO2FCdeE>

The monitoring of the child's development and "anticipatory guidance", i.e., helping parents understand what comes next in the child's development and their role in promoting these next steps in development, is something that you will do during each of your visits. It is something that is best done in the home, the natural environment of the young child and family.

Based on research we know that a child's health and development are closely linked. Home and clinic visits may help to identify health-related risk factors, like medical conditions or malnutrition (including overweight and obesity) or micro-nutrient deficiencies that can affect child development. In home visits, you will also look at how the child is functioning in various domains of development and the risk and protective factors within the child's immediate and more distal environments (for example, the availability of community services). Your interactions with and questions to the parents, observations of their interactions with the child, and response to your feedback will enable you to see how the child is progressing.



Here are key steps you can follow to monitor a child's development during your home visits:

1. **Explain to parents what you mean by child development** - You may need to explain the various components of development such as language development and communication, cognitive development, motor development, social-emotional development, self-regulation, play and self-help skills. Often parents think that the term "development" and "growth" are the same. It is important to explain to them what the domains of development are and that all domains should be considered. Although the various domains of development are related, the child may have difficulty primarily in one domain (e.g., motor skills in a child with cerebral palsy) or in several of them.
2. **Inquire about the parents' concerns** – The parents' concern about the child's development is a crucial component of developmental monitoring. As the primary caregivers, they know their children best, and you can obtain invaluable information by giving them the opportunity to voice their concerns. You can use an open ended question such as *"By child development I mean how your child communicates, understands, relates, plays, sees, hears, moves, learns and does things for herself. Do you have concerns about your child's development in any of these areas?"* Knowing about caregiver concerns is an important step that paves the way for monitoring child development and providing feedback to the parents. The answers given to such a question also help you understand how the parents' perceive their child's progress. It should be noted however that although this question is the crucial starting point, there are caregivers who may not voice their concerns or may not understand the developmental difficulties that the child may be experiencing. Furthermore, the mother and father may differ in their opinion, and it would be important to establish a common understanding and agreement on how to proceed.

3. **Monitor and support expressive and receptive language.** Delays in language development are the most common and often earliest signs of developmental difficulties. The home visit enables you to obtain information about the child's intent to communicate and the mode in which s/he communicates (gestures, sounds, words). You can observe caregivers efforts to stimulate language skills and praise these efforts. You can also show caregivers how to enrich the child's language environment. You can explain the importance of the child interacting with the parent, and that television viewing and computer games hamper early childhood development. Parents should be encouraged to talk to their children and show pictures and read children's books or even before age 6 months. You can prepare and share a list of children's books that are appropriate for infants and can be found in the community.

4. **Monitor and support movement.** You can observe how a child uses his/her limbs, trunk (gross movement) and hands and fingers (fine movement), for example by placing the infant on a blanket and observe his/her movement. If there are any problems in movement, you can examine the child to see if muscles are hypotonic or hypertonic. Prompt referral is necessary in case of delays in movement development and/or if there are any signs suggestive of neurological problems. Explore and support opportunities for movement in the home and outside with the caregivers.

5. **Monitor and support the child's emotional regulation.** An important sign of social and emotional development is the child's ability to regulate his/her emotions especially when he/she is overwhelmed or distressed. The home visit provides you with many opportunities to observe emotional regulation and how parents support this process. You can observe and point out positive examples, as this important part of development is often overlooked by parents. Comments such as "Look how well he recovers after being upset about something. The way you were soothing and calming him really helped."

6. **Monitor the child's relatedness.** Relatedness is how the child initiates interactions and interpersonal relationships with others. Observe the child's eye-contact, affect, reciprocal interactions and engagement with the parents, other family members and strangers (you or other visitors). How the child relates to inanimate objects such as toys or other objects is also important. Lack of deep, meaningful prolonged eye contact, inability to sustain interactions and reciprocal play, lack "joint attention" (i.e., the baby or young child may lack interest in what other people are doing or what they are watching for) may be important observations that may need referral for further evaluation. Lack of relatedness may be due to autism which has a high prevalence of approximately 1/100. It could also be due to problems in attachment or severe stressors such as neglect or abuse. Prompt referral for evaluation is necessary, if you have concerns. Actions you can take to promote greater relatedness include
 - Discuss your concern with the parents
 - See if there seems to be neglect or abuse
 - See how much time the child spends in interactions with parents, other caregivers and family members and see how you can increase quality interactions and social play
 - Make sure that the family follows through on any referral and a proper evaluation of the child, if recommended.

7. **Monitor play activities and mutual engagement.** Families may not understand how important social play is for their child's development. Explain to the family that "play is truly the child's work". (*see also the Module 6 The Art of Parenting – Love, Talk, Play, Read*) It involves building skills in all developmental domains, like social and

emotional development, cognitive development, language, motor development, and self-regulation. To find out more about the child's play, ask the parent/caregiver about their child's typical day; find out what they do for fun; see what toys or objects the child and family plays with together and who plays with the child. Building on the child's level of development and the activities the family enjoys, propose new activities that could strengthen developmental domains that appear to be delayed or affected. If the family is already involved in an intervention program, ask how it is going and see how playful behavior and mutual enjoyment can be integrated into daily exercises.

8. **Monitor protective factors including the support provided by caregivers.** Observe the interactions of the child with the parents/caregivers. Are they warm and nurturing or tense and stressed? How do parents talk about their child and his/her development? Is the mother supported by others? What is the role of the father? Are there other caregivers that contribute to the care and development of the child? Knowledge about protective factors at home and in the outside environment also provides an opportunity for you to praise the family's efforts to support their child's development. Use your expertise and offer advice on what else can be tried and anticipatory guidance to achieve the next milestones.

9. **Monitor developmental risks factors.** Your relationship with the parent/s or care givers can open the door to talk about other factors that influence the child's development, for example, parental wellbeing (maternal or paternal depression, anxiety, etc. – (see *Module 7 on Parental Wellbeing*), physical or other mental health issues in the family, financial problems, history of substance abuse or family violence, and the developmental opportunities provided by the home environment. Inadequate stimulation in itself or associated with any of the above conditions may constitute a risk for development. You can support the parents and family by listening with empathy, suggesting resources and services that the family may be able to access, emphasizing the need to minimize the effect of these risk factors on the child. In addition, you can emphasize that expensive toys are not needed for development and help the family use readily available household items and activities for play.

10. **Monitor the family's strategies to minimize risk factors, the need for additional services and creating a follow-up plan.** If the child has a disability or obvious developmental difficulty, you will need to work with the family to help them find effective strategies to address these risk factors. For this, you should be knowledgeable about community resources that can be helpful to the family and child, and make referrals when necessary. Once a plan for supporting the child's development is established, it is important to follow-up with the family during your subsequent visits, so that the outcome of the plan and need for additional support can be monitored, and you can act as the family advocate if they encounter difficulties accessing these services or working with new providers.



Case study

A new family was just added to your caseload – a single mother with two young daughters. The mother is middle class, recently divorced, and has moved into the area where you are doing your home visits. The older girl is 4 years old. She is a healthy, happy, and very active little girl. The baby is 11 months. The mother is still on maternity leave, but is already under stress thinking that she will have to return to work right after the first birthday of her younger daughter. The younger girl was born prematurely with intrauterine growth

retardation, but according to the mother’s opinion, she is developing well. The mother is very caring, but she doesn’t have anyone around who could help.

You observe that the younger girl still is not crawling, and is unstable in a sitting position. Her mother tells you that she is very calm, sleeps a lot, is easy to please and not very interested in her environment. The mother thinks that the little girl has an easy temperament and is relieved about that. She is wondering what it would be like, if her younger daughter was as active and demanding as the older one.



Reflection and discussion

Using the steps listed above, what have you observed and heard, what else might you want to find out?

Step	Observed	What else would you want to know?
Mother’s concerns		
Expressive and receptive language		
Motor development		
Emotional regulation		
Relatedness		
Play and mutual engagement		
Protective factors		
Risk factors		
Family strategy to minimize risk		
Need for additional services?		

Some ideas:

Step	Observed	What else would you want to know?
Mother’s concerns	Return to work, child care, managing 2 young children with different needs	Family and supportive network, availability of family or friends to care for the baby
Expressive and receptive language of baby	Not observed	Observe routine care activity or mother-play
Motor development of baby	Delayed, even taking into account IUGR	Observe fine motor skills

Step	Observed	What else would you want to know?
Emotional regulation of baby	Calm and apparently not very engaged in surroundings	Observe how baby responds when faced some challenges (e.g., some food or toy that are out of reach)
Relatedness of baby	Limited engagement with people and objects	Observe and find out from mother how baby responds in playful interactions and caregiving routines
Play and mutual engagement	Mother reports limited interest in the environment	Observe routine care activity or play, also between the baby and older sister
Protective factors	Mother caring and warm	Are there relatives or friends that could support the mother and her children
Risk factors	Reported “easy temperament” may reduce engagement and learning opportunities for the baby	Mother may not understand the need to stimulate the development of her baby. Baby may receive less nurturing care after mother returns to employment
Family strategy to minimize risk		Does mother have family or friends in the area? How is she feeling after the divorce? What is the role of the father with both children? Arrange for meeting with the father, if possible.
Need for additional services?		Should the baby receive a formal assessment? Is older sister enrolled in pre-school? Are there early intervention services or play groups the mother could attend with the baby?

V

TOOLS FOR DEVELOPMENTAL MONITORING AND SCREENING

1. MONITORING CHILD DEVELOPMENT USING DEVELOPMENTAL MILESTONES

While each child is unique, early child development generally occurs in predictable steps and stages. Tools that use developmental milestones for monitoring child development are based on this premise. Such tools can provide you with an age range when a child is expected to be able to do a certain activity, and there are “red flags” that indicate a concern when a child is not showing a certain behavior or is not engaging in certain activities. In addition, some tools may also provide you with activities or ideas to stimulate further development.



UK (2014). *What to expect, when?* The set of materials for children from 0-60 months (see link below) describes at what approximate age behaviors or skills can be observed and what parents can do to stimulate their child’s development.

http://www.foundationyears.org.uk/files/2015/03/4Children_ParentsGuide_2015_WEB.pdf

United States Center for Disease Control. *Developmental Milestones*. This set of materials describes what most children can do and when to contact the provider for assessment.

http://www.cdc.gov/ncbddd/actearly/pdf/checklists/all_checklists.pdf



Video clip - Recognizing Child Development Problems / Educational Video courtesy of CDC.

From birth to 5 years, your child should reach milestones in how he plays, learns, speaks and acts. A delay in any of these areas could be a sign of a developmental problem, even autism. The good news is, the earlier it is recognized the more you can do to help your child reach her full potential. Early recognition of developmental disabilities such as autism is key for parents and providers... Less than half of children with problems are identified (in the U.S.) before starting school. During this time, the child could have received help for these problems and may even have entered school more ready to learn.

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

Monitoring using the Guide for Monitoring Child Development (GMCD). This open-ended interview tool with caregivers was designed to monitor and support child development and the early detection and management of developmental difficulties. It measures domains relating to expressive and receptive language, gross and fine motor skills, social skills, play skills and self-help skills. A number of countries in the region have professionals that were trained in this new tool (Ertem et al 2008).

2. DEVELOPMENTAL SCREENING TOOLS



Note. The use of screening tools by the home visitor is a country decision. Sections not-relevant to your country can be deleted from this module.

Here are several helpful screening tools. You can add others that home visitors use in your country or that they should know about.

Ages and Stages Questionnaire. The ASQ-3 identifies potential delays and helps determine which children need further assessment or ongoing monitoring. It measures five domains: communication, gross motor, fine motor, problem solving, and personal-social. It is completed by the parent, takes about 15 minutes to complete, and is then scored by the professional. It covers ages from 2 – 60 months. The ASQ-3 has been translated into a number of languages (Serbo-Croatian, Georgian, Russian). For more information, see www.agesandstages.com.

Piccolo Tool. This tool (see Information Card 1) looks at the many ways parents can be supportive of their young child's development, what they believe is important, what they feel comfortable doing in front of others, and what they know how to do with their child. The behaviors that were included in the tool are useful to keep in mind with any family with a 10 – 47 months old child that you visit, and Piccolo scores have been found to predict school readiness. The Piccolo looks at parenting behaviors in four domains: affection, responsiveness, encouragement, and teaching. Each domain includes 7–8 parenting behaviors. Research has found that for children with identified disabilities, parents with higher Piccolo scores had children who did better on cognitive and language outcomes.

The Modified Checklist for Autism in Toddlers-Revised (M-CHAT-R™) is a scientifically validated tool for screening children between 16 and 30 months of age for risk of autism spectrum disorder (ASD). To look at the tool, click here: <https://www.autismspeaks.org/what-autism/diagnosis/mchat>

3. MONITORING OF OTHER FACTORS TO IMPACT ON EARLY CHILD DEVELOPMENT

A number of factors – such as parental mental health and the home environment – can contribute to developmental difficulties, and some home visiting services are using the tools described briefly below:

Maternal wellbeing. The Edinburg Postnatal Depression Scale (EPDS) is designed to detect postnatal depression in mothers 6-8 weeks after delivery. It is a short (10-item) self-administered tool originally designed to identify the presence of depression in women following childbirth at the community level, although it has been used during pregnancy and other periods, including with fathers and translated into a number of languages. The scale measures symptoms of depression including sadness, fear, anxiety, self-blame, and sleeping difficulties. This tool has also been used with fathers.

<http://www.psychiatrictimes.com/all/editorial/psychiatrictimes/pdfs/EdinbPostDepScale.pdf>

For more information look at the Module on Parental Wellbeing!

The home environment. The most commonly used tool is The Home Observation for Measurement of the Environment (HOME, Caldwell & Bradley, 2001). The HOME can be used in the home environment to determine the amount of care, nurturing and stimulation provided to children. It has been used in Serbia, tFYRoM, Russia, and Turkey. The Infant/Toddler (IT) HOME Inventory includes six subscales: 1) parental responsivity, 2) acceptance of child, 3) organization of the environment, 4) learning materials, 5) parental involvement, and 6) variety in experience. It measures the quality and quantity of stimulation and support available to a child in the home environment. The focus is on the child in the environment and the child as a recipient of inputs from objects, events, and transactions occurring in connection with the family surroundings.

These tools require some training, but have been used by home visiting professionals in a number of countries.

4. WHAT YOU NEED TO KNOW ABOUT FORMAL ASSESSMENT

Formal assessments of children with disabilities or suspected developmental delays or developmental difficulties are usually conducted by specially trained professionals. A pediatrician, who also assesses the child's physical health in addition to other domains, is often the first person to start the assessment process.

A formal assessment is usually comprehensive (assesses all or most areas of development), and other specialists may be included for special concerns (audiologist, ophthalmologist, infant mental health specialist, physiotherapist, speech and language specialist, etc.). Given the limited number of specialists in most countries, such assessments may only be provided in limited central locations, i.e., tertiary hospitals in the capital city, NGOs. The assessment specialist or team often uses tools that are standardized and validated in the country or region.

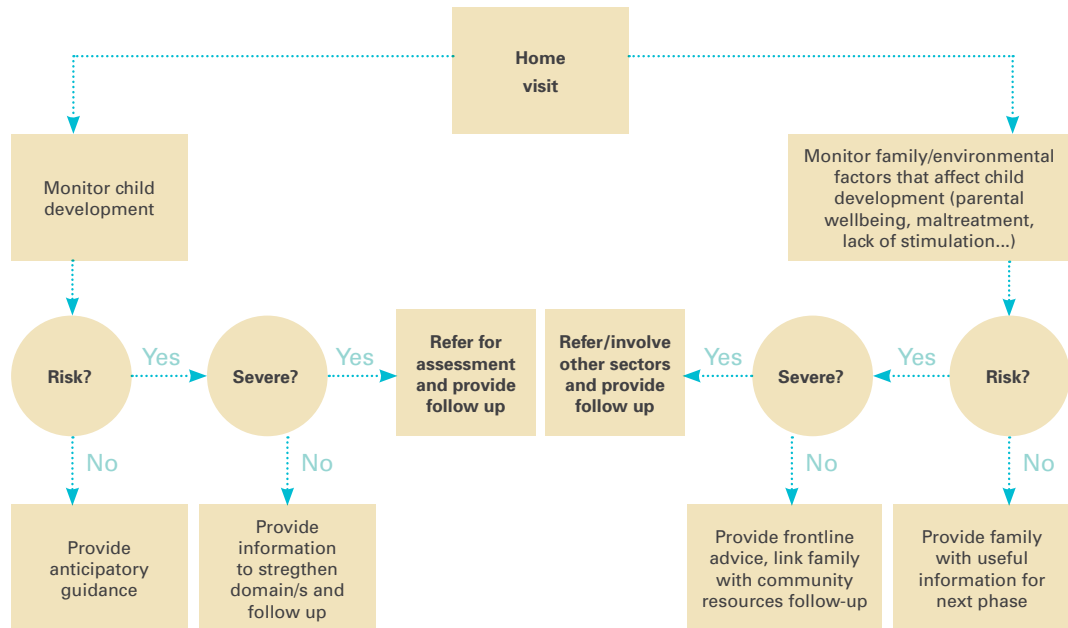
It is now becoming a best practice to include the parents and/or important family members in the assessment process, as they generally know most about the child's ability to function in daily life, the child's strengths, weaknesses, vulnerabilities, and the support needed for optimal development. The family's involvement in the assessment process, i.e., a family-centered process, is based on our understanding that the family's concerns for the child, their hopes for the future, as well as their capacity and willingness to support the child's development constitute the most important facilitators or barriers to development.

When, unfortunately, experts have not involved the family in the assessment process, but only received a debriefing, they may look to you to explain some of the test findings, what these mean to the child now and for the future, how they can access the recommended intervention services, and if eligible, the processes needed for the child to receive disability benefits. You should be familiar with the assessment report and get clarifications from the primary professional involved in the assessment.



VI

WHAT TO DO WHEN YOU THINK THAT A CHILD IS AT RISK FOR DEVELOPMENTAL DIFFICULTIES OR DELAYS



During your home visits, you will observe the child, listen to the parents, and look at the overall parenting and family environment.

- If the child is developing normally and the environment is responsive and nurturing, you can provide reassurance, support positive parenting, and provide anticipatory guidance, i.e., information about what comes next in development and how to continue to support the health and wellbeing of the child.
- If the child has a developmental risk or difficulty due to factors related to the child, the family or the overall environment, but you think this situation can be remedied with advice or additional support, you can suggest additional activities or services to the family or provide some basic interventions yourself.
- If either the developmental difficulty is more severe or the family factors too complex to be addressed through home visiting support, you need to refer the family, and if necessary help the family in following through with the referral. As discussed in the *Module 2 on The New role of the Home Visitor and the Module 15 Working with Other Sectors*, you will continue to provide basic support to the family, while collaborating with your colleagues from other sectors.



Generally, a young child is considered delayed if his development or behavior differs from 90% of his/her age mates.

Whatever the developmental progress of the child, in all situations, use every opportunity to share ways of enhancing child development and wellbeing with parents, caregivers, and the whole family. It is always important to not solely focus on the child, but to see the child in the context of the family and the larger environment.

VII

DISCUSSING DEVELOPMENTAL DELAYS WITH PARENTS AND FAMILIES

Successful and efficient communication with parents and family members about developmental delays and/or difficulties will be demanding on you and require your skills and understanding of each parent's perspective and feelings over time (*See also the Module on Caring and Empowering – Enhancing Communication Skills for Home Visitors*). The most important skills in your conversations with parents are good listening skills and showing empathy for their situation. You will need to closely monitor the parents' reactions during your communications with them and be aware that parent may differ in their response and ways of dealing with a child that is developing differently. But they will always need your empathy and your understanding. Keep in mind that parents' feelings and abilities to cope are likely to change over time and that parents may not respond in the same way (*see also the Module 12 on Children Who Develop Differently – Children with Disabilities or Development Difficulties*)

Here are some typical situations you may encounter:

Telling parents that their child may have delay and should be assessed

You may wonder why you should even tell parents that you have noticed some delays or developmental difficulties in the way or rate with which their child learns new skills or communicates with others, when it is so stressful for parents to hear this.

There is always the possibility in some cases that these red flags will disappear and that the development will be within the normal range. Ofcourse, this is possible, but at this point we do not know if that will happen. Taking a strategy of "watching and waiting" is not good. Every day in the child's life is important and has to be filled with the best possible opportunities for learning and development. Children who are delayed or show some worrying signs of developmental difficulties need additional learning opportunities, here and now. It is likely that parents will need professional guidance to provide this additional support to their child.

Your best approach – keeping the child in mind – is therefore to calmly tell parents about your concerns. You may recommend an assessment to better understand how the child is experiencing the world and to identify the specific needs that should be addressed to promote his/her development.

It is important to explain that the outcome will always be better if some additional strategies are incorporated in the daily routines because they improve the child's learning and interactions with others. You should also bear in mind that it has been shown that an early diagnosis can have a long-term positive effect for the whole family: It starts the process of parental coping and adaptation to the child's disability and, consequently, the creation of a supportive environment for the child.

Having difficulties in dealing with the existing services

This is likely to be a difficult issue for both you, and the families you are supporting. Often there are long waiting lists for assessments, and parents may have to visit many different agencies and experts (different medical doctors, psychologists, speech and language specialists, physical therapists, etc.). They may have to repeat the same information about the child and family a number of times, will hear inconsistent and vague explanations because experts do not cooperate with each other, and feel confused.

First, it is important to help families establish this contact with experts. You will need your skills in accessing experts and working with other sectors (*See Module on Working with Other Sectors*) to provide this kind of support. Assessments may be performed by services in the health, education or welfare sector, and sometimes the service depends on the child's specific difficulty. In a number of countries, this service may also be provided by NGOs or private specialists.



It is important that you have a good knowledge of what services are available in your community, and what services may only be available in major cities or in the private sector.

In addition to this, the parents will need your help in finding early intervention services. Assessments without intervention don't make much sense, but sometimes parents receive a diagnosis and/or their child is registered for disability benefits, but are lacking good guidance of what to do next. It is important to connect assessments with the appropriate support, but this is something that does not always go smoothly in our countries.

Many parents go to private services to shorten the process of wandering and waiting, and pay for it out-of-pocket. It is important to encourage all parents to ask the experts to explain their findings and recommendations, and to provide concrete next steps for the child and the family.

Sometimes you will notice another problem. Some experts indicate examinations, especially medical tests, where parents fail to understand the reasons for why they are needed. It is important to encourage parents to ask for explanations to understand what additional information these test results might provide, and how they will make a difference in planning the interventions for the child. You may find test results in the child's file or parent folder and recommendations for yet further tests. Unfortunately, interventions may be postponed because "something else should still be checked" and valuable time is lost to promote the child's development.

Helping families understand assessment results

When talking with the parents or caregivers, it is helpful to ask them first what they already know about the assessment, the results the child has achieved, and how they feel about it. The conversation is better if it is built on what the parents are already familiar with.

In doing so, always talk about the child, using his/her name, and any kind of generalization or demonstrative pronouns, such as "that, those, these... children" should be avoided. Parents should know that an assessment says very little, if anything at all about the future outcomes. The main purpose of the developmental assessment is to get an insight into areas of strength as well as weaker aspects of the developmental profile of the child to be able to support his or her learning at a given time.

It is also important to understand family needs and to provide the support. The needs the family has chosen as priority should be your focus. According to research, one of the most pronounced family needs is the need for information. Besides information about the assessment and what the results mean, the family will need a lot of information about behavioral issues and the learning needs of the child and how these could impact the overall quality of life of the child and the family.

In many cases assessments may not lead to a diagnosis or a reason for the disability or the developmental difficulty. In such situations, it may be important to help the family focus on what on the child's needs for development rather than spending valuable energies and resources on a quest for answers. The publication below can provide you with additional information you can use with families.

http://www.cafamily.org.uk/media/655450/about_diagnosis_living_without_a_diagnosis_feb_2013.pdf

Providing other necessary information

The parents of children with disabilities have significantly increased needs for information. Every day they are faced with new and unexpected situations arising from the child's specific developmental and behavioral patterns. Furthermore, to be able to make decisions about raising their child and to gain access

to appropriate services and programs, they will need a lot of information. Don't worry if you can't answer their questions immediately. Make sure to tell them that you will seek further assistance to solve the issue. Also, remember that it is sometimes enough for the parents only to be listened to.

Remember that today families can find a lot of information on the internet, but sometimes the information has to be filtered and discussed. Families may be vulnerable to the promise of "false cures" or therapies. If the family has developed a relationship of trust with you, you can help connect them with reliable sources of information. Other families that have experienced or are going through similar challenges or associations of parents of children with disabilities can also provide information and peer support. Discuss the possibility of connecting families with families that have similar needs a colleague's caseload, when the involved family is open to this.



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VIII

SUPPORTING FAMILIES AFTER A CHILD HAS BEEN ASSESSED



This **video clip** explains what early intervention can look like when it is integrated into the child's life and the family's routine.

<https://www.youtube.com/watch?v=8fOJGmldj0c>

Your role with the family does not end with the family entering early intervention services or other support services. Often these types of services are still provided primarily in practitioner offices, clinics or health centers, and the family will then need to apply what they have been taught in their daily routines in the home or community settings. For this and for the general ongoing support, they will need the continuum of care you can provide to them. Some of the things you can do to prepare yourself include:

- If possible, in the ideal case, you will be welcomed into the team of professionals that provides intervention services to the child and family, in "the team around the child"
- Learn about the child's assessment results and recommendations for interventions and consider how you can help families overcome barriers to integrating what they have learned into daily routines
- Know what organizations in the community can provide relevant services to support the family. These may not be linked directly to the intervention, but may provide parents with "respite" or breaks in the care of their child, access to important resources (special equipment and materials), NGOs or parent organizations that provide information, counseling, advice, or, simply, peer support, etc.
- Be aware of barriers that will affect the family's participation in intervention and follow-through with practice in the home and provide the intervention team with alternatives, if possible.

When visiting the family,

- Be aware that after the first assessments, families will have many questions about information they did not understand or new concerns that have emerged.
- Help the family find additional sources of information and support when they are ready for it. If they are not open to some information during a visit, they may be ready to listen another time. Remember, the parents and family are going through many changes as they are adapting to parenting a child that has additional needs.
- Show families how what they are learning can help them with their daily routines and how these practices can be integrated to help their child develop.
- Help parents to not become locked into a role of being their child's trainer, but find opportunities and times to enjoy playful interactions and take into account their own needs, as well as the needs of other family members.



Additional resources

Motor development. Pediatrician Lisa Shulman shows the motor milestones expected in typically developing babies, from head control to walking and what pediatricians look for during a well-baby visit. She also explains the specific types of motor control a baby must master

before the next milestone can be achieved. Dr. Shulman is associate professor of clinical pediatrics at Albert Einstein College of Medicine and an attending physician in pediatrics at The Children's Hospital at Montefiore. She is also director of the RELATE program for the diagnosis and treatment of autism and related disorders at Einstein's Children's Evaluation and Rehabilitation (CERC).

<https://www.youtube.com/watch?v=G5wVVNYLBVk>



Language and Communication Milestones. In this public service video for parents, Lisa Shulman, M.D., uses a video of babies and toddlers to show the communication milestones expected in typically developing children. She also discusses what parents should do if they suspect their child is developmentally delayed.

<https://www.youtube.com/watch?v=pZSjm0drlGM>



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IX

ANNEX



INFORMATION CARD 1



29 THINGS PARENTS DO THAT PREDICT SCHOOL READINESS

Below are 29 things parents do with their young children, ages 10-47 months, that predict one or more of the following outcomes when children are old enough to start kindergarten:

Cognitive skills (problem solving, reasoning, science, and math readiness)

Vocabulary (word knowledge, language ability)

Literacy skills (recognizing letters, linking speech sounds to letters, recognizing text)

Social skills (emotion regulation, low rates of aggression)

Our research, on over 4,000 observations of almost 2,000 families, shows that very few parents do all of these things, but all parents do some of these things. And the more parents do these things, the better their children do on school readiness assessments. PICCOLO™ is an observational measure of these behaviors.

- | | |
|---|--|
| <ol style="list-style-type: none"> 1. Speak warmly 2. Smile at child 3. Praise child 4. Stay physically close to child 5. Say positive things to child 6. Interact in positive ways with child 7. Show emotional warmth 8. Pay attention to what child is doing 9. Change activities to meet child's interests or needs 10. Be flexible when child changes interests 11. Follow what child is trying to do 12. Respond to child's emotions 13. Look at child when child talks or makes sounds 14. Reply to child's words or sounds 15. Wait for child's response after making a suggestion | <ol style="list-style-type: none"> 16. Encourage child to do things with toys 17. Support child's choices 18. Help child do things on his or her own 19. Verbally encourage child's efforts 20. Offer suggestions to help child 21. Show enthusiasm about what child does 22. Explain reasons for something to child 23. Suggest activities to build on what child is doing 24. Repeat or expand child's words or sounds 25. Label objects or actions for child 26. Engage in pretend play with child 27. Do activities in a sequence of steps 28. Talk about characteristics of objects 29. Ask child for information |
|---|--|

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PICCOLO: retrieved from <http://www.brookespublishing.com/resource-center/screening-and-assessment/piccolo/>



REFERENCES

Caldwell BM, & Bradley RH. (2001). HOME inventory and administration manual. (3rd ed.). University of Arkansas for Medical Sciences and University of Arkansas at Little Rock.

Ertem IO, Dogan DG, Gok CG, Kizilates SU, Caliskan A, Atay G *et.al.* (2008). A Guide for Monitoring Child Development in Low- and Middle-Income Countries, *Pediatrics*, 121, e581-e589.

PICCOLO tool: <http://www.brookespublishing.com/resource-center/screening-and-assessment/piccolo/>



