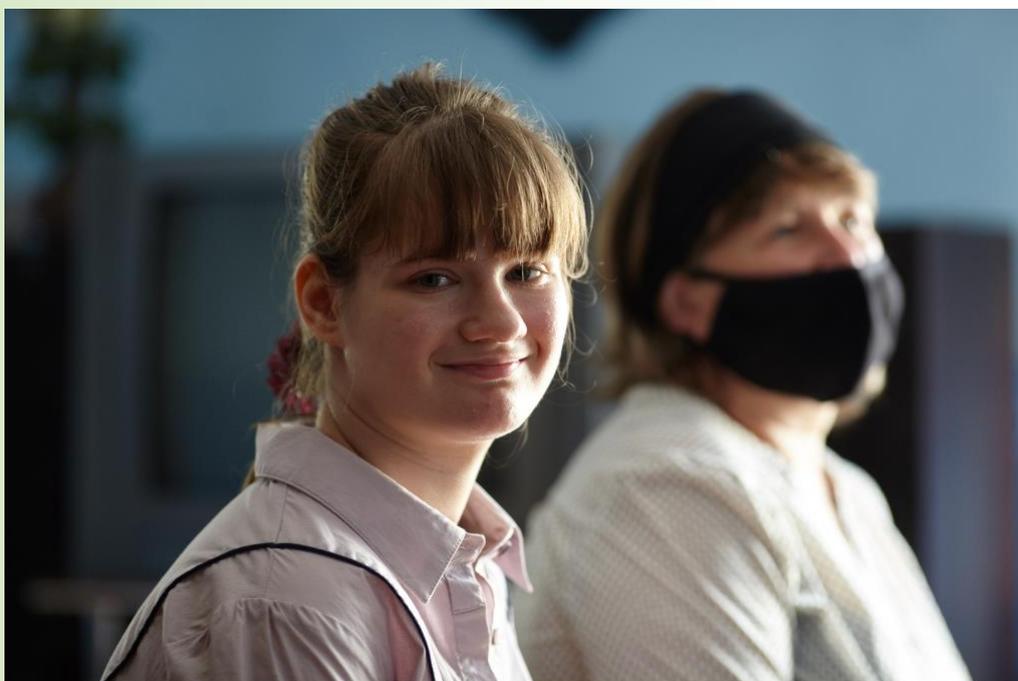


# Changing THE WAY WE care



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## Toolkit for Disability Inclusion in Care Reform

**Facilitator's Guide:  
Introduction to  
Identification of  
Developmental  
Delay and Disability**

# Acknowledgement

The **Toolkit for Disability Inclusion in Care Reform** was produced by *Changing the Way We Care*<sup>SM</sup> (CTWWC), an initiative designed to promote safe, nurturing family care for children. It represents a collection of work developed from the experience of many practitioners. This facilitator's guide for the **Introduction to Identification of Developmental Delay and Disability** and the accompanying training slides were designed by disability and care reform practitioners and consultants for CTWWC with an aim is to build the capacity and confidence of those working in family strengthening and children's care for work with children with disabilities and their families. We thank the following people and organizations: Elayn Sammon, Gwen Burchell, Leia Isanhart, Kupenda for the Child, Catholic Relief Services, and the CTWWC teams in Kenya and Guatemala for their input, feedback and pilot testing.

As *Changing the Way We Care* and partners learn from and promote family care we commit to full and meaningful inclusion of children with disabilities and their families throughout the process of care reform and all of our work. Children with disabilities disproportionately live in residential care and are, too often, the last to be deinstitutionalized. We commit to putting them first.



Changing The Way We Care<sup>SM</sup> (CTWWC) is a Global Development Alliance funded by USAID, the MacArthur Foundation and the GHR Foundation, and implemented by Catholic Relief Services and Maestral International, along with other global, national and local partners working together to change the way we care for children around the world. Our principal global partners are Better Care Network, Lumos Foundation, and Faith to Action. CTWWC's vision is to be a bold global initiative designed to promote safe, nurturing family care for children, including reforming national systems of care for children, strengthening families, family reunification and preventing child-family separation, which can have harmful, long-term consequences, development of alternative family-based care, and influencing others to build momentum towards a tipping point of change for children.

**Need to know more? Contact *Changing the Way We Care* at [info@ctwwc.org](mailto:info@ctwwc.org) or visit [changingthewaywecare.org](http://changingthewaywecare.org)**

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# Glossary

<b>Advocacy</b>	Advocacy is when people get support to speak up. It is a process of supporting and enabling people to express their views and concerns, access information and services, defend and promote their rights and responsibilities and explore choices and options.
<b>Advocate</b>	(1) The person who supports another through the advocacy process. (2) The act of advocacy
<b>Alternative care</b>	A formal or informal arrangement whereby a child is looked after at least overnight outside the parental home, either by decision of a judicial or administrative authority or duly accredited body, or at the initiative of the child, his/her parent(s) or primary caregivers, or spontaneously by a care provider in the absence of parents. Alternative care includes kinship care, foster care, adoption, <i>kafala</i> , supervised independent living, and residential care.
<b>Child</b>	A child is a person under 18 years of age, unless otherwise defined by national definition
<b>Child protection system</b>	A comprehensive system of laws, policies, procedures and practices designed to ensure the protection of children and to facilitate an effective response to allegations of child abuse, neglect, exploitation and violence.
<b>Community-based Inclusive Development</b>	An approach that brings change in the lives of people with disabilities at community level, working with and through local groups and institutions. CBID addresses challenges experienced by people with disabilities, their families and communities in practical ways.  These enhance and strengthen community-based rehabilitation (CBR) as it has evolved over the last decades.
<b>Developmental delay</b>	Refers to a child's developmental skills developing later than expected, compared to others of the same age. Delays may occur in the areas of motor function, speech and language, cognitive, play, and social skills. Delays can indicate a disability, but not always – many children with delays catch up.
<b>Disability</b>	Disability is a long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder a person's full and effective participation in society on an equal basis with others (UNCRPD).

<b>Discrimination</b>	Discrimination happens when individuals or institutions unjustly deprive others of their rights and life opportunities due to stigma.
<b>Family</b>	Refers to those within the caring circle of a child; those providing daily emotional, physical and psychological care. This caring circle varies according to culture and circumstance; thus, the use of the term family recognizes that in many societies the care environment of a child is broader than the parents of birth or immediate family and includes the extended family, sometimes called <i>kinship network</i> . Families have primary caregivers who can be birth, extended relative, foster or adoptive parents, in some instances, child-, grandparent-, or single parent-headed. CTWWC further expands the term to include families who are providers of family-based alternative care, such as <i>foster family</i> .
<b>Habilitation</b>	This is a process aimed at helping disabled people attain, keep or improve skills and functioning for daily living; its services include physical, occupational, and speech-language therapy; various treatments related to pain management; and audiology and other services that are offered in both hospital and outpatient locations. <sup>1</sup>
<b>Inclusion</b>	Inclusion involves a full reform, which means that children with disabilities can participate fully in the life of the family and community. This means making changes to the environment, the way we all communicate, our attitudes/belief systems and the way we provide services.

<sup>1</sup> See RI Global <http://www.riglobal.org/projects/habilitation-rehabilitation/>.

<b>Independent living</b>	<p>Here a young person or adult with disabilities is supported in her/his own home, a group home, hostel, or other form of accommodation, to become independent. Support/social workers are available as needed and at planned intervals to offer assistance and support but not to provide supervision. Assistance may include timekeeping, budgeting, cooking, job seeking, counselling, vocational training and parenting.</p> <p>Independent living/living independently means that individuals with disabilities are provided with all necessary means enabling them to exercise choice and control over their lives and make all decisions concerning their lives (see UNCRPD General comment on Article 19: Living independently and being included in the community). For children with disabilities, this involves ensuring that, in line with their evolving capacities, they have the same freedoms as typically developing children to make choices in life, and that they receive support for the choices they make.</p>
<b>Occupational therapy</b>	<p>This focuses on helping people with a physical, sensory or cognitive disability to be as independent as possible in all areas of their lives. It can help children and adults with a disability improve their cognitive, physical, sensory and motor skills and enhance their self-esteem and sense of accomplishment.</p>
<b>Participation</b>	<p>Participation is exercising the right to be listened to and to involvement in decisions and actions that affect the one participating (such as child participation) and to have those views taken into account.</p>
<b>Physiotherapy</b>	<p>Physiotherapy is science-based profession that helps restore movement and function when someone is affected by injury, illness or a disability. It can also prevent deterioration and further loss of function through a maintenance program of rehabilitation based on individual treatment plans.</p>
<b>Rehabilitation</b>	<p>Rehabilitation refers to regaining skills, abilities or knowledge that may have been lost or compromised as a result of acquiring a disability or due to a change in one's disability or circumstances.<sup>2</sup></p>
<b>Reunification</b>	<p>The physical reuniting of a separated child and his or her family or previous caregiver.</p>

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<sup>2</sup> Ibid.

<b>Reintegration</b>	The process of a separated child making what is anticipated to be a permanent transition back to his or her immediate or extended family and the community (usually of origin), in order to receive protection and care and to find a sense of belonging and purpose in all spheres of life. Re/integration can also refer to the process of a person with disability, who has been institutionalized, making a transition back to living in the community.
<b>Residential institution</b>	A large institution is characterized by having 25 or more children living together in one building. A small institution or children's home refers to a building, housing 11 to 24 children. Can also refer to a facility housing adults with disabilities.
<b>Self-advocate</b>	This is a child or individual who has the skills knowledge and support to advocate on their own behalf.
<b>Speech and language therapy</b>	These support children and young people who have a speech disorder (a problem with the actual production of sounds) or a language disorder (a problem understanding or putting words together to communicate ideas). They work on augmentative and alternative communication, which are the methods used to supplement or replace speech or writing for those with impairments in the production or comprehension of spoken or written language.
<b>Stigma</b>	Stigma refers to attitudes and beliefs that lead people to reject, avoid or fear those they perceive as being different.
<b>Typically developing child</b>	This describes a child who meets the usual developmental milestones within the usual timescales.
<b>UNCRC</b>	The United Nations Convention on the Rights of the Child is a legally binding international agreement and human rights instrument setting out the civil, political, economic, social and cultural rights of every child, regardless of their race, religion or abilities.
<b>UNCRPD</b>	The United Nations Convention on the Rights of Persons with Disabilities is a legally binding international agreement and human rights instrument that reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms.

This facilitator’s guide accompanies the workshop slides by the same title, **Introduction to the Identification of Developmental Delay and Disability**. It is designed to be used by the person providing the workshop, often called “the facilitator” or “the trainer”.

**It is suggested that participants complete the half-day workshop on disability inclusion included in Toolkit for Disability Inclusion in Care Reform as a foundation for this workshop.**

Each session section of this guide provides the facilitator with a script; however it should not be read verbatim but rather adjusted to the facilitator’s own style. *Scripts will appear in italic font.*

The section description includes content for lecture with accompanying slides, suggested handouts, and exercises.

The facilitator’s guide uses the following symbols to guide the facilitator:



Discussion



Community example



PowerPoint Slide



Written exercise



Question & Answer



Hand out

# Introducing the Workshop

The workshop should begin with participant introductions, followed by any announcements such as the duration of the sessions, timing of the breaks, location of facilities and issues of confidentiality. The latter is important to ensuring participants feel they can speak up and express ideas and opinions freely. All participants should understand that personal information and stories/experiences shared in the workshop remain in the workshop, even while they are welcome to share learning content with others. If required, confidentiality agreements should be signed as participants enter the workshop and their attendance is noted.

## Tips for virtual introductions and ice breakers

- Ask participants to use video whenever bandwidth allows – this helps to keep attention. Alternatively, ask speakers to use video while others turn video off
- Use a neutral “get-to-know” question: where are you joining from?
- Ask people to “pass the mic” to someone else, i.e. call on the next person in turn
- Turn off all videos, using a list of questions, “turn your video on and wave if you answer yes” Example, if you are a social worker, if you have more than two online calls per day, or more fun, if you had eggs for breakfast, if you were born in March, etc.
- Organize a scavenger hunt – give a list of things participants go away and find – first person to come back with all items wins (e.g. “something living” “something to eat” “something summer” “something red”)
- Depending on time, have participants in small breakout rooms to get to know each other. Provide a list of question or guidance. Example, what their biggest recent work success?

**For an on-line / virtual workshop** the introductory session should include instructions on using the virtual platform, muting/unmuting, hand raising, how and when to ask a question, and use of any other functions, online tools to be used. All features for accommodation such as closed captioning, sign or other language interpretation, should be arranged and tested ahead and the introductory session should include review of how to use these features and

## Interactive online workshop tools

- Mentimeter helps you build interactive presentations and polls – smart device friendly [www.mentimeter.com](http://www.mentimeter.com)
- Google’s Jamboard is a digital interactive whiteboard – [www.google.com/jamboard/](http://www.google.com/jamboard/)
- Platforms like Zoom, MicroSoft Teams, GoogleMeet and others have ability for break out rooms and white boards
- Use Kahoot to make trivia games or fun training quizzes – [www.kahoot.com](http://www.kahoot.com)

how and who to communicate accommodation requests to. Handouts should be emailed or otherwise made electronically available before each session start, and participants should know who to connect with technology or attendance issues.

**In person workshop** introductory sessions should include instructions on: how and when to ask a question, (e.g. hand raising, written questions answered at the end of each session, etc.), agreed ground rules such as listening with no interruption, mobile phone and laptop usage; switching off mobile phones, closing laptops and accessing break rooms and facilities, etc. Sign language or other interpretation should be arranged in advance and how and who to communicate accommodation requests to must be made clear, including mobility accommodations.



### Slide 1. Introductions & purpose

*“Welcome to this one-day introduction to identification of developmental delay and disability workshop. My name is ... I come from ... (locality, country). I have ... (type/years of experience in) ...*

*Please introduce yourselves and tell us your name, where you come from and why you are attending this training.”*

Consider using one of the icebreaker exercises you know or suggested in the boxes above.

*“This is a learning workshop for people like yourselves who are working or who will be working with children and families to promote safe, nurturing family care for children. Some of you might be working with children in residential care (sometimes called orphanages, children’s homes, or insert your country’s term) and others with children at risk of child-family separation. The workshop was developed by the Changing the Way We Care initiative out of a desire to make sure that disability is included in their work and yours.”*

Here you might also introduce the organization you work for, if different. The workshop may also be useful for others who work with children and families, both government and non-government. Adjust this introduction to meet the characteristics of the participants. This training is generic so that it is applicable in any context; however, it asks that those involved think about the environment in which they work when making decisions about how to proceed at each step.

# What is Disability Inclusion?



Disability is a driving factor for isolation, separation from family, lack of access to education and institutionalization of children in residential care facilities. Due to their complex needs and social barriers to inclusion, children with disabilities are often the first to be placed in residential care and the last to leave or be reunified in family or community. They can also be the hardest children to see and locate in the community, because they face stigma and discrimination and thus are sometimes kept hidden.

*“Some of you will know children with a disability who live in your neighborhood. Some of you will have worked with children who have a disability and with their families, and some of you may not have very much experience at all in this field. Yet others of you may have your own personal experiences with disability.*

*This workshop will provide you with enough information to be more confident in discussing developmental delay and disability when you are working with children and families, talking to people in your community and when you are working with others about the work that you are doing. Beginning this conversation can be one of the first steps in making the community inclusive, so that children with disabilities can live well, grow and develop at home; all children currently in institutions can come home to live in a family; and families can feel supported and able to care for their children.”*

The learning workshop provides participants with information, but it should also include time for them to think and reflect the own attitudes, beliefs and behaviors, and to ask questions openly.

*“As we go through the material together, you might have some questions. If you think these questions can wait until the end of the session, please write them down as a reminder. If you think you need an answer to the question immediately—because it will help you understand the topic—please raise your hand – others probably have the same question!*

*Because we are all individuals, we each have different knowledge, skills and experience. Much of this is informed by where we grew up, the people we grew up with and our personal life-events. This workshop uses lots of examples – please be free to share your own.”*

Because this workshop is designed for people living in different contexts, a broad range of examples from different countries are included, but there will be gaps. As facilitators you are encouraged to bring your own examples or to ask participants for some. Learning will be applied better with contextually appropriate examples.



## Slide 2. By the end of this workshop...

At the end of the workshop, participants will be able to describe:

- what early identification and early intervention mean and why they can help give a child the opportunity to maximize their developmental potential and quality of life;
- the purpose of the International Classification of Functioning, Disability and Health; measuring functioning and the UNICEF/Washington Group Child Functioning Module; statistical data collection; and other assessment tools;
- methods for identifying children with developmental delay and disability in the community and in their work; and
- methods to minimize the impact of developmental delay and disability on children and their families.

As the facilitator you might ask here if any participant has any other expectations for the workshop.

*“Before we move on, we need to remind ourselves about the definition of disability.”*



## Slide 3. Defining Disability

*“Throughout this workshop we will be talking about children with developmental delay and children with disabilities.”*



Early identification of a developmental delay can lead to early interventions to reduce the impact of the delay on the child’s life now and into the future. This means that children are less likely to experience activity limitations or participation restrictions if we intervene early. Some other children will clearly have a disability—for example, because they have a congenital condition or impairment (one they were born with) like Down syndrome or cerebral palsy—which will impact them for life, but others may be developing at a different pace than their peers, for example maybe they do not articulate their speech or maybe they are not learning to walk. This is especially important as we consider children in residential care facilities, for whom research indicates increased likelihood to have developmental delays because of the environment of congregate (or group) care.

**Disability** is a long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder a person’s full and effective participation in society on an equal basis with others.

A **developmental delay** refers to a child's developmental skills developing later than expected, compared to others of the same age. Delays may occur in the areas of motor function, speech and language, cognitive, play, and social skills. Delays can indicate a disability, but not always – many children with delays catch up.

# Why Early Identification and Early Intervention Are Important



## Slide 4. What exactly do we mean when we say early identification and early intervention?



For all children, systematic monitoring of early growth and development is important for identifying any delays in meeting developmental milestones and to make sure that when a delay is identified, children get the help they need as soon as possible. **At this early age— from pre-birth until starting school—a focus on developmental milestones rather than definitive diagnosis of disability will increase the chances for early intervention, which will improve a child’s opportunities and minimize the effect of any delay.**

*“When we talk about child development, we often speak of **milestones** that children hit at certain ages. So, what exactly are these milestones? It can be helpful to understand them and how they can be used to guide the assessment of development.*

*You can think of the **developmental milestones** as a checklist. They represent what an average child can do around a particular age, although this obviously varies from child-to-child.”*

A **developmental milestone** is an ability that most children achieve by a certain age. These milestones can involve physical, social, emotional, cognitive and communication skills—such as walking, sharing with others, expressing emotions, recognizing familiar sounds and talking.

To illustrate, between 9–12 months, children begin to achieve physical milestones—such as sitting, standing or walking. While the exact age at which a child achieves a particular milestone can vary, parents and professionals may become concerned if a child hasn’t achieved a skill that most of his/her same-age peers can perform or if he/she hasn’t achieved skills in more than one area of development. This should prompt a visit to the child’s doctor, who can check to see if there is a problem.

**Early identification** means finding out, as soon as possible, if a child has any delays in meeting developmental milestones.

**Early intervention** means getting the child needed help as soon as possible, to reduce the longer-term effect of a developmental delay.



A visiting community health worker liked to see the village children playing together. One day she realized that Hana, a happy, smiling 3-year old girl, always played by

herself. She asked Hana's parents why the little girl didn't play with the other children. They told her that Hana didn't speak. The community worker spent some time with Hana and did some simple tests. She realized that Hana did not speak because she could not hear. The community worker was then able to show her family some different ways to communicate, including standing in front of Hana so she could see them when they spoke to her, and using gestures to communicate with her. The community worker also began to investigate the sign language used in her country and spoke to associations for deaf people to find out where they could get more help.

In many countries, well-child visits to the community nurse or doctor includes a checklist of development. This is a tool health professional use to make early identification of development delays.



### Slide 5. Why are early identification and early intervention important?

First, early identification and intervention are important because it is a child's right. Children with development delay or disabilities are children with their own needs, wants and rights. As for all children, children with developmental delays or disabilities have the right to thrive—not simply survive. This means they have the right to participate fully in their families/communities and access the services needed to help them achieve their potential. These rights are protected and advocated for by the United Nations Convention on the Rights of the Child (UNCRC) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

These Conventions mandate that governments ensure children with disabilities have:

- the right to life, survival and development;
- the right to early intervention and early identification; and
- the right to early intervention services designed to minimize and prevent further disability.

**All the provisions of the UNCRC apply to all children.**

Second, all children deserve the best possible start in life. Too many children face the kind of disadvantages that affect their development and threatens their future health, happiness and ability to be productive citizens. Early identification of these difficulties can play a part in offering children and their families the early intervention support they need to reach their full potential.

The early years—from pre-birth until starting school—is a critical period in terms of a child’s development; one of the main reasons is how fast the brain grows beginning before birth and continuing into early childhood. Although the brain continues to develop and change into adulthood, these early years can build a foundation for future learning, health and life success. Children form bonds with their parents, develop language skills and other cognitive functions and establish behavioral patterns. Gaps that emerge in the early years can persist into the school years and beyond. Early intervention has a vital role to play in identifying children who may be showing **atypical development**, and in helping to develop the skills and competencies that set a child up for life.

Some disabilities may not be visible. This means that the disability is not immediately obvious, For example, you may not immediately know that a child is deaf if you cannot see a hearing aid. A child’s learning disability may not become obvious until he/she begins school. As a worker who comes into contact with children and families regularly, it is very important that you consider if a child has a hidden disability, which is a barrier to their full participation. You can do this by thinking and checking about developmental milestones.



**Written exercise.** Take three minutes to write down three reasons why early identification is important for children.

Ask each person in the group to read out what they have written and put it up on the board/flipchart/screen.



**Discussion.** *As a group, discuss what services for early intervention you can think of in your community.*



**Handout 1. Some additional reading on early brain development and developmental milestones**



*“Before we move on to the next section do you have any questions?”*

# Purpose of Assessment Tools

Assessment tools include the International Classification of Functioning, Disability and Health; the UNICEF/Washington Group Child Functioning Module; and others. When talking about identifying disability, many people mention the International Classification of Functioning Disability and Health (ICF). *To understand the ICF it is important to first know a little bit about assessment, screening and diagnosis.*



## Slide 6. Assessment, screening and diagnosis

Understanding and appropriately responding to a child's disability depends for the most part on adequate assessment of developmental delay. Early identification is important because a child's development is most rapid during his/her early years and mitigating measures taken at this stage can reduce the impact of a delay.

*"You may hear different terms used from time-to-time to describe this process."*

In the context of early identification, **assessment** refers to the continual monitoring of developmental milestones. In some countries this is a systematic process which can involve home-visiting nurses or clinicians who review children at regular intervals, such as when they come for vaccinations. This can also be the responsibility of volunteers who work in local communities on maternal and newborn health, such as village health workers.

In some countries there is a mechanism for **newborn screening**. This involves testing every child for specific indicators so that a treatment regime or early intervention activity can be initiated to prevent the condition becoming disabling. Newborn screening can involve a physical examination to check the eyes, heart, hips and, in boys, the testicles (testes). It can also include a hearing test to identify hearing loss as early as possible, and a blood test to detect rare but serious conditions such as sickle cell disease, cystic fibrosis, congenital hypothyroidism and other inherited diseases of the metabolic system. The most common condition for which screening exists is congenital hypothyroidism—a disorder affecting the thyroid gland, which is in the neck. The thyroid gland produces a hormone (chemical substance) called thyroxine, which is needed for normal growth and development. If this is not treated a child can experience difficulties with mental development, learning and clumsiness. This newborn screening process means that a condition can be identified as early as possible, and an appropriate intervention planned to mitigate the effect of the condition. It is important that countries balance the costs of a screening program with the possible benefits.

In the medical model of disability, the term **diagnosis** is often used. This is because parents and professionals often believe that if they can diagnose the child, they can then take steps to treat and cure. While newborn screening can identify specific conditions—which can result in interventions to prevent the condition, impacting in a child’s opportunities for growth and development—many conditions cannot be diagnosed, and even for those that can, there may be no treatment options. **Waiting for a diagnosis before beginning an early intervention program can increase the negative impacts of a developmental delay.**



### Slide 7. The International Classification of Functioning, Disability and Health

Because it can be difficult to establish a medical diagnosis, the World Health Organization (WHO) recommends that diagnosis should be based on a person’s capacity to function. They have published guidelines and a common framework for the assessment of disability in **clinical and research contexts** called the International Classification of Functioning, Disability and Health (ICF). This fits with the UNCRPD definition of disability, which includes activity limitations and participation restrictions.

The people who use the ICF to assess disability are usually trained medical and social sector professionals—for example, pediatricians, speech therapists, physiotherapists, psychologists and social workers—who work together in a team to complete the complex assessment. The ICF is generally used for statistical purposes, such as in a national population census to collect prevalence data on disability.

In some countries, governments use ICF (or an adapted ICF) to assess if a child or adult is eligible for disability-related benefits. This is a formal process decided by a panel of experts according to standard procedures and guidelines.

There are other international tools which are commonly referenced—one of which is the Washington Group/United Nations International Children’s Emergency Fund (UNICEF) Question Set on Child Functioning. This follows the ICF focus on functioning with the intention of producing internationally comparable statistical data on children. It was developed to be applied using **data collection during household censuses and surveys.**

The Washington Group on Disability Statistics is a group established under the United Nations Statistical Commission. This working group was constituted to address the urgent need for cross-nationally comparable population-based measures of disability. The module on child functioning has been developed in conjunction with UNICEF.

In some countries people adapt the Washington Group/UNICEF question set to use it as a day-to-day assessment tool. This is only useful and ethical if the people who use this scientific tool have been properly trained and the local language translations have been tested and

validated. Otherwise, it can be subjective and thus open to interpretation and possible incorrect results. Incorrect results or assumptions about a child’s functioning can lead to misinterpretation or misdiagnosis around disability.

Other commonly used tools for understanding development include the Ages and Stages Questionnaire (ASQ), which provides reliable, accurate developmental and social-emotional screening for children between birth and age 6. Drawing on parents’ expert knowledge, ASQ has been specifically designed to pinpoint developmental progress and catch delays in young children, paving the way for meaningful next steps in learning, intervention or monitoring. ASQ is not an autism screener; however, it reliably picks up delays associated with autism and identifies children who should receive further evaluation. The publishers of ASQ operate a licensing process and usually issue a license when they can be assured that a mechanism for appropriate application and institutionalization of the tool is in place.

A more in-depth assessment of motor skills, cognitive development and communication of infants and toddlers, ages 0–3, is the Bayley Scales of Infant Development (BSID-III) and takes between 45–60 minutes to administer. Scores are used to determine the child’s performance compared with norms taken from typically developing children of their age.

Testing these scales for validity and reliability in the local population is highly recommended, because mistranslation of language and terminology can affect measurement outcomes.

Since ASQ is a self-administered parental questionnaire, the results should be interpreted by a trained professional—usually a nurse or pediatrician—and the BSID-III is designed to be administered by trained professionals.

## Other Examples of Standardized Tools for Child Assessment

These are included in Handout 2. See also [www.disabilitymeasures.org](http://www.disabilitymeasures.org).

### Denver Scale

- Appropriate for children 0–10 years
- Provides clear indication of the developmental age of the child with respect to language, communication, social, motor, cognitive and autonomy
- Relatively simple scale to use and requires few materials
- Appropriate to use in initial assessment and for continuous assessment and monitoring
- Can be applied by those with basic training

### Portage Scale

- Appropriate for children 0–5 years
- More detail of development than the Denver Scale
- More complicated than the Denver Scale but can be used by those who have received training

### Special Needs Evaluation Form

- Appropriate for children with medium to severe special needs
- Adaptive Behavior Scale (ABS-RC 2) that reflects the needs and experiences of children with special needs.

### Supports Intensity Scale (SIS)

- A standardized assessment tool to measure the pattern and intensity of supports that a person aged 16 years and older with intellectual disability requires to be successful in a community setting
- The SIS focuses on skills the individual has and what is required to gain independence

### Gross Motor Function Classification System, Expanded and Revised (GMFCS E&R)

- For children with neurodevelopmental disabilities affecting gross motor skills, such as Cerebral Palsy
- Uses illustrations for children in the range of 6–12 years and 6–18 years

### Manual Ability Classification System for Children with Cerebral Palsy (MACS)

- For children with fine motor difficulties, using either Mini MACS for children below the age of 4 years or MACS for children 4–18 years

### Communication Function Classification System (CFCS)

- For children with communication impairments

### Communication Matrix

- An assessment tool to help families and professionals easily understand the communication status, progress and unique needs of anyone functioning at the early stages of communication or using forms of communication other than speaking or writing



## **Handout 2. Assessment, screening/diagnosis and ICF**



*“Before we move on do you have any questions?”*

# Methods for Identifying Children with Developmental Delay and Disability



## Slide 8. Talking to people in your community

In some countries, children with developmental delay and children with disabilities are part of their communities and are very visible. In these cases, it is possible for you to have a conversation with the child’s family or primary caregiver about how to support the child to achieve his/her potential and realize their rights, and how to support the family to access services.

**In some countries and communities, it is more difficult to know where children with disabilities live because they are not a visible part of their community.** To begin to locate these children, you should be sensitive to the stigma and discrimination which exists in your local context. Sometimes families who are asked “Does your child have a disability,” or, “Do you have a child with a disability?” will say “no” to these questions. They may be keeping their children hidden because of the stigma, or they may not have noticed or accepted that their child has some developmental delays. They may be frightened. You can work with the family to build a relationship by discussing the needs of other children—before you address the issues of their child with a disability.

This is also important when you are thinking about reintegrating a child from an institutional setting to their own family or to alternative family-based care. Helping families talk about their child positively means *you* should talk about their child positively. If they placed the child because of fear, stigma and discrimination, this might be the first time someone is talking positively about their child. This can help them think about the reintegration process more thoughtfully rather than rejecting the idea outright. Similarly, when you are talking to people about fostering a child with a disability, they may reject the idea; however, if you use your knowledge about disability and children’s rights, and can talk respectfully about children with disabilities, this can help them to think about choosing to foster a child with a disability.

Likewise, you should also talk about disability with community leaders, friends, family and colleagues. Involving existing community structures which are close to families—for example, community health workers, home visiting nursing service and community child protection case management workers—can be effective in locating children with disabilities who may benefit from your support and prepare the community to receive children coming back from institutional care. Talking about disability is a critical piece of preventing separation of children from families and it is a first step in helping a family and community advocate for the services they need as well as being important in breaking down stigma and discrimination.

You can also talk about these issues with the families you meet in your day- to-day work. If you know a family whose child has a disability, ask them if they know any other families who might need support. In this way you can let people know that you understand the issues and that you have the skills to help.

It is also important to contact any organizations representing people with disabilities—to know where they are and what they do. They can give you advice and information and may be able to put you in touch with a person in your area who has a disability as well identify those who can work together with you on local advocacy. Equally important is to identify any organizations who serve people with disabilities so you can connect families and children with disabilities to available support. We have prepared separate guidance on how to map services and set up a service directory.



*“Before we move on do you have any questions?”*



### **Slide 9. Assessment**

Once you have identified a child with a disability or a suspected developmental delay, you will do an assessment of his/her strengths and needs in the same way you would for any child and family who comes to your attention. This can be a child living in the community already, or a child you are preparing to move back to his/her community. This means collecting information, then analyzing and discussing with the child and his/her family to find out what support could help and be provided. There are many different types and levels of assessment for children and families and there are also targeted assessments for children with disabilities. In some countries there may be tools that are already well known and used widely; in other countries you may be introducing something new.

During this process you may use:

- the standard assessment tools for children and families which are part of your current case management system—this will include the assessment of the families’ living conditions and child-family relationships which can be enhanced to assess the specific needs of a child with disabilities and his/her family, as well as a look at the child’s development, strengths and access to education; and
- checklists specifically developed to quickly assess developmental delay in children, which are ideally part of your case management toolbox (see Handout 2).

The checklists for assessment of developmental delay can be standardized across your organization. A toolkit of recommended curricula and assessments is provided as an accompaniment to this training.

During this assessment process you should make sure you have addressed all the child's support requirements by making sure you have involved everyone in the child's life. This can mean talking with health care providers, schools or any other relevant people who are involved or who you think should be involved in the child's life.

Involving everyone includes the children themselves. Make sure you ask them about their feelings, interests and opinions. Spend time with each child talking and observing to find out about his/her strengths, as well as any difficulties they experience or needs they perceive.

For more experienced practitioners, there are a range of resources for assessing childhood developmental delays or disability. However, in many cases, these require an organization to pay for a license to use the g. This is because the developer of the assessment tool(s) wants to make sure that they are being properly used by fully qualified workers. In some cases, because the resource has been developed for use in a particular country context, the tool also needs to be validated to make sure it is appropriate in a different context.

Learn more about assessment tools which can be used by more experienced practitioners. These resources usually have an associated cost and can be expensive. They are usually introduced through national or regional programs. Check to see if there are any clinics or organizations in your country that offer such screenings and use them if warranted.

- Ages and Stages Questionnaire (ASQ)
- Bayley Scales Infant Development (BSID)
- Childhood Autism Rating Scales (CARS)
- Transdisciplinary Play-based System (TPBA 2 and TPBI 2)

You can also check out the assessments mentioned in Handout 2.

Because a child may experience difficulties in more than one area of development, they may need to be assessed by a team who are specialists in different areas. This can include social workers, physiotherapists, occupational therapists, speech therapists or other specially trained rehabilitation technicians. They can be found in clinics, hospitals or specialist rehabilitation centers—or you can find out if community-based rehabilitation is part of your local community programming. You can also contact any organizations representing or serving people with disabilities in your area or country.

Assessments of children with disabilities should consider the individual and unique characteristics of each child and his/her family and take full account of functioning, strengths and any factors that may hinder the achievement of outcomes for children in their:

- physical and mental health and emotional well-being;
- protection from harm and neglect;
- early childhood experiences, education, training and recreation;
- contribution to society and social relationships; and
- social and economic well-being.

The assessment should consider the needs of the child, the strengths and needs of the parents/carers—including how looking after the child impacts his/her life, the environment in which the child is living—including how safe and suitable it is, and the support networks for the child and family. In a case management process, goals for addressing any need for supports, bolstering strengths of the family and addressing impacts of the environment should be considered in case planning and referral to services.

The assessment is completed in partnership with the family and other professionals and will include the views of the child and his/her caregivers. The worker completing the assessment should ensure that families are given information about the Assessment Tools, and an explanation of how they are completed and used.

One of the reference toolkits widely used is called [Disabled Village Children](#). This guide for community health workers, rehabilitation workers and families was developed for people who live in villages and poor communities where they never see a “rehabilitation expert” or a “physical therapist.” This does not always mean that they have no “rehabilitation” or “therapy.” In many villages and homes, family members, local craftspeople, traditional healers and disabled people themselves have figured out ways to do things better and move about more easily. Information is included in Handout 3.



### Handout 3. Assessment



*“Before we move on do you have any questions?”*

# Methods to Minimize the Impact of Developmental Delay and Disability



Take three minutes to write down three ways you can start to minimize the impact of developmental delay and disability on children.

Ask each person in the group to read out what they have written and put it up on the board/flipchart/screen.

Consider what we have written as we go through the next section.



## Slide 10. Early intervention services

Early intervention services can include:

- more in-depth assessment by trained multi-disciplinary professionals;
- immediate referral to habilitation and rehabilitation services, including supported referral if necessary, to ensure the family receives the services;
- advice pamphlets for families, particularly around understanding child development and how to foster it;
- referral to family support groups, parenting skills training and other family-strengthening services;
- specialist home-visiting services for children with developmental delays or disabilities; and
- learning through play opportunities and inclusive early childhood programs.

If medical staff in local clinics are aware of the needs of children with developmental delays and disabilities, they can make special provisions to accommodate the child. This can mean simply making sure the building is physically accessible so that the child can enter to be seen by a doctor, nurse or other specialist. Or it can be more complex and require training of personnel on children's rights and the special care required for physical and cognitive learning and development.

If there is a home-visiting service, such as midwives who visit mothers and babies at home after delivery, that is a key opportunity to detect delay in the child's development not identified at birth and to give the family advice and information in stimulating and observing the development of their child.

Providing information to families and communities about things like basic child development, rights/entitlements, availability of local services/supports and simple things they can do at

home to stimulate development, can help create an environment where children can learn/develop and families feel capable to meet their needs.

The [Disabled Village Children](#) guide for community health workers, rehabilitation workers and families includes many ideas for helping children develop and become more self-reliant.

# Innovations and Ideas

In this section we are going to consider some different mechanisms for working with children with disabilities and their families to support early identification and early intervention. You can find out if these are available in your community or if it is possible to introduce them.



## Slide 11. Community-based Rehabilitation Guidelines

While not designed exclusively for children, CBR is a movement that is working toward inclusive communities. The global guidelines focus on inclusion in the domains of education, health, livelihood, social development and empowerment. The CBR guidelines can provide useful background information for anyone promoting an inclusive community where early intervention is a component. You can find out if there is a CBR movement in the community where you live and talk to them about advocacy and ideas for early intervention.

CBR upholds the belief that people with disabilities not only have needs specific to their disability but also have needs and rights as individuals that many different actors can help them fulfill. CRS/CTWWC staff don't need to provide *all* the solutions—they are only a *part* of the solution and have a contribution to make. Additionally, they can/should collaborate with whoever else supports children of disabilities and their families.



### Discussion. What could CBR look like in your community?



## Slide 12. Learning through play

If a child's development is delayed, one of the most effective early intervention measures is learning through play. Play is essential in the development of all children and is how all children learn. And play is something that children just do—you don't need any special training or materials to play. This can be as simple as a child putting a safe toy in his/her mouth to understand how it feels, to throwing something to see what happens.

Playtime is also an opportunity for families and caregivers to develop a loving bond with their child, which is very important for brain, physical and social development. International research shows that the interaction in these early months and years is linked to the child's potential and happiness as an adult. Playtime is also an important time for families to get to know their child and to notice what his/her development is like.

Most children will instinctively try to play with anything in reach from their birth onwards—they are driven to play. If the child has a disability or developmental delay, then families and

other caregivers can use play as a way to promote learning and development. Too often, adults think that if the child can't play, then they are not interested. In reality, they may just need help to learn how to play. Play helps children socialize and learn from each other and can help reduce stigma and discrimination when disabled children and typically developing children play together.



#### **Handout 4. More information about learning through play**

One of the easiest and most instinctive methods of early intervention to “build brain architecture” is sometimes called “serve and return” or “act and react.”



#### **Video. [Parent chatting with his child](#)**

This viral video is a great example of the principle of serve and return.

Serve/return and act/react interactions shape brain architecture (links to more information on brain development and the effects of neglect are included in Handout 5). When an infant or young child babbles, gestures or cries, and an adult responds appropriately with eye contact, words or a hug, neural connections are built and strengthened in the child's brain that support the development of communication and social skills. Much like a lively game of tennis, volleyball or ping-pong, this back-and-forth is both fun and capacity-building. When caregivers are sensitive and responsive to a young child's signals and needs, they provide an environment rich in serve and return experiences.

Because responsive relationships are both expected and essential, their absence is a serious threat to a child's development and well-being. Healthy brain architecture depends on a sturdy foundation built by appropriate input from a child's senses and stable, responsive relationships with caring adults. If an adult's responses to a child are unreliable, inappropriate or simply absent, the developing architecture of the brain may be disrupted, and subsequent physical, mental and emotional health may be impaired. This is true for all children; children with development delay or disability need this interaction just as much as typically developing children. We can help caregivers understand this. The persistent absence of serve and return interaction acts as a “double whammy” for healthy development: not only does the brain not receive the positive stimulation it needs, but the body's stress response is activated, flooding the developing brain with potentially harmful stress hormones.



#### **Handout 5. More information about brain development and the effects of neglect**



*“Before we move on do you have any questions?”*

# Re-cap



## Slide 13. What you have learned

One of the reasons why children are separated from their families is because they have a developmental delay or identified disability, and the family does not know how to access services, is afraid of stigma or may feel they do not know how to raise the child.

In your day-to -day work in your community you can: spend some time explaining why identification and early intervention can help give children the opportunity to maximize their strengths, developmental potential and quality of life; get to know more about the methods for identifying children with developmental delay and disability in your community; identify the services that exist including organizations that support people with disabilities; and continue learning methods to minimize the impact of developmental delay and disability on children.

You will be given all the course materials to take with you, to read and to reflect.



*“Before we finish this learning workshop, do you have any questions?”*



If there is time, ask participants what they will take away from today’s learning to use in their work.

# Facilitation Tips

## Choosing the Right Facilitator

Getting the right facilitator helps participants to feel more comfortable joining in and benefiting from the training. Consider:

- Do you want someone in your organization to facilitate or an external facilitator? Think about the pros and cons of someone who is more objective and who knows your organization better
- Do you want a male or female facilitator?
- Do you want more than one facilitator? Whilst this can require more resources, it can help in terms of giving participants more support, securing a gender balance in the room and/or in situations where there is a local language that only some participants use. Your organization should obtain references for external facilitators, as well as an induction to the organization.

## The Facilitator's Role

It is the facilitator's responsibility to:

### Prepare well:

- As a minimum, familiarize yourself with:
  - the training handouts and slides
  - the facilitator's guide
- Do background research that will make you feel more comfortable leading it. You can use the resources from the toolkit
- Make sure you have the required materials and tools or use the materials you have available and adapt the training accordingly
  -
- Choose a quiet location for the training to take place / review online and virtual training tools and resources
- Know or find out about participants. Tailor the length and content of each activity to suit the group. *Be prepared that some activities may raise particularly sensitive issues. It is important you are aware of referral mechanisms in case you come across a concern or disclosure*
- Adapt activities so that they are relevant to participants
- Incorporate local examples
- Add or remove questions to make sessions more relevant

- Adjust the length of the sessions to meet participants' needs and the number of participants. If you're working with a big group, the activity is likely to take longer

*During the training:*

- Set ground rules with participants at the start of the training, including turning mobile phones to silent; listening to each other; not judging each other
- You may choose to start with an icebreaker: a short, fun activity to encourage participants to relax and get to know each other. It can be as simple as telling the person next to you what your favorite pastime is; they then feedback to the whole group
- Give participants the opportunity to ask questions and check that participants understand the instructions clearly before beginning each activity
- Lead and monitor activities making sure everyone has opportunities to participate and be listened to
  - Do not force anyone to participate. Make the group aware that they do not have to participate and can stop participating at any point throughout the activity
  - Respond appropriately – take action if you observe that a participant does not feel listened to, able to participate, or in need of additional support. Follow up in line with the organization's safeguarding policy if someone appears upset or distressed, or raises a concern
  - Keep promises you make - to let participants speak, take breaks or not take part if they don't feel they want to.
- End on a positive note outlining the key learning points so participants understand they took the training and how they can use it in their work

# Workshop Handouts

## Handout 1. Additional reading - developmental milestones

You can find more about the importance of early life experiences for brain development [here](#).

### Birth-to-age-6-months typical development timeline

1-4 weeks old-- loves looking at faces and begins to recognize family members/primary caregiver, may be startled if they hear loud and sudden noises

4-6 weeks old -- starts to smile and respond to the sounds around them

4-12 weeks old -- lifts their head while lying on their front

3-5 months old -- reaches out for objects as their muscles develop

4-6 months old -- starts making noises, enjoys making new and different sounds

5 months old -- lifts objects and tries to suck on them

6 months old -- hand-to-hand coordination, will learn to pass things from one hand to another

6-8 months old -- sits without support

*\*Adapted from NHS Choices Birth to five development timeline*

- UNICEF East Caribbean developed this [video resource](#) to demonstrate developmental milestones in children.
- This UNICEF Uganda [video resource](#) on early childhood development discusses the importance of caring for children in the early years.
- There are many different checklists available to find out if a child is meeting typical developmental milestones. These can also be used by families who can then discuss any concerns with you or with a specialist during the child's regular health check-up. These include:
  - Pathways.org [checklists](#) are for children from birth to 6 years
  - Centers for Disease Control (CDC) checklists have descriptions of the usual milestones and what you/family members/caregivers can do to help children learn and grow - CDC [checklists](#)
  - The development [checklist](#) is especially for family members.
- You can also check-out the [Disabled Village Children](#) as well as the accompanying manuals for helping [children who are deaf](#) and [children who are blind](#). These contain detailed checklists and visual aids, including pictures of developmental milestones, which are especially useful for people who may have difficulties with literacy. This resource has a small cost.
- The [National Portage Association](#) also provides resources for early identification and early intervention.
- [UNICEF's Early Child Development Toolkit](#) is designed to help program planners and managers to understand the best start in life for children.
- The Global Health e-Learning Centre, a USAID initiative, offers six different on-line certificated training courses in [Early Childhood Development](#)

Changing the Way We Care

*Facilitator Manual: Identification of Developmental Delay & Disability*

Handouts

## Handout 2. Where you can find more information about assessment, newborn screening and diagnosis and the ICF

The links to these materials is provided for information only. It is recommended that application of these scientific tools and instruments is undertaken only after an accredited training process.

- This 2015 article provides [global data on newborn screening](#) programmes.
- Information about congenital hypothyroidism from Great Ormond Street Hospital for Children in the UK can be found [here](#).
- The UK National Health Service has published a [guide to newborn screening](#) for parents.
- The USA Centers for Disease Control and Prevention (CDC) has a [Newborn Screening Portal](#) with access to general information, resources and tools.
- If you have limited experience the [ICF eLearning Tool](#) can help you understanding the ICF model and classification terms, furthermore, this course will help you learning how to apply and use the ICF in practice.
- The [ICF Practical Manual](#) is another good place to start to learn more. It provides information on:
  - getting started with the ICF;
  - how the ICF is used to describe functioning;
  - how it can be used in clinical practice and for the education of health professionals;
  - how it can be used to plan for community support services and income support;
  - for population-based, census or survey data;
  - for developing or adapting education systems;
  - for policy and program purposes; and for
  - advocacy and empowerment purposes.
- Learn more about the [ICF](#) at the World Health Organisation website; and the ICF for Children and Youth [here](#).
- World Health Organization. How to use the ICF: [A practical manual for using the International Classification of Functioning, Disability and Health \(ICF\)](#). Exposure draft for comment. October 2013. Geneva: WHO
- UNICEF has worked with The Washington Group on Disability Statistics to develop [specific sets of questions on child functioning](#). These take the ICF into consideration. There are two questionnaires, for children aged under 5 and for children aged 5 to 17 which can be used to collect statistical information and data about children with disabilities in national household questionnaires and population surveys.
- The UK National Autistic Society provided information about [autism profiles and diagnostic criteria](#).

## Handout 3. Assessment

*The links to these materials is provided for information only. It is recommended that application of these scientific tools and instruments is undertaken only after an accredited training process.*

Additional reading on checklists for developmental milestones is included with Handout 1.

- Example of a [needs assessment matrix](#) for children with disabilities. This can be used in alongside the usual child and family assessment included in your case management package.
- This [needs assessment matrix](#) can also be used to consider what additional resources a child with a disability may require depending on the level of identified need.
- For more experienced practitioners there are a range of resources for assessing childhood disability. However, in many cases these require an organization to pay to hold a license to use the product, which can be expensive. This is because the developer of the assessment tools wants to make sure that they are being properly used by fully qualified workers. In some cases, because the resource has been developed for use in a particular country context, the tool also needs to be validated to make sure that it is appropriate in a different context.
- Learn more about assessment tools which can be used by more experienced practitioners. These resources usually have an associated cost and can be expensive. They are usually introduced through national or regional programs.

### **Ages & Stages Questionnaires®** [ASQ](#)

- Provides reliable, accurate developmental and social-emotional screening for children between birth and age 6. Drawing on parents' expert knowledge, ASQ has been specifically designed to pinpoint developmental progress and catch delays in young children—paving the way for meaningful next steps in learning, intervention, or monitoring. ASQ is not an autism screener; however, the ASQ reliably picks up delays associated with autism and identifies children who should receive further evaluation.

### **Bayley Scales Infant Development** [BSID](#)

- Examine all the facets of a young child's development. Children are assessed in the five key developmental domains of cognition, language, social-emotional, motor and adaptive behaviour

### **Childhood Autism Rating Scales** [CARS](#)

- One of the most widely used and empirically validated autism assessments. It has proven especially effective in discriminating between children with autism and those with severe cognitive deficits, and in distinguishing mild-to-moderate from severe autism.

**Transdisciplinary Play-based System [TPBA 2 and TPBI 2](#)**

- A natural, easy-to-use assessment and intervention approaches for children birth to age 6. Trusted for more than 25 years, this popular, highly effective system helps you get accurate assessment results, develop customized play-based intervention plans, identify children's service needs, and evaluate child progress. At the heart of the system is a fun and naturalistic play session where children are relaxed and engaged. Focusing on what children can do instead of what they can't, TPBA2 elicits more meaningful and accurate results than many traditional assessment strategies. Assessment data is easily linked to individualized, play-based intervention activities with TPBI2.

## Handout 4. Early intervention through play

These are just a few of the many resources about learning through play. Many of the toolkits are designed for work with a child who is developing typically, and the same principles are relevant for children with disabilities.

- Scope UK have produced this [video resource](#) about encouraging inclusive play.
- This open source book, [Play Development in Children with Disabilities](#) has information about developmental play with children who are visually and hearing impaired, who have intellectual disabilities and/or multiple disabilities, communication difficulties etc.
- [Play and Children with Disabilities. Interdisciplinary Perspectives](#) is a Journal published by the Center of Research in Child-Parent Interaction. This edition is intended to raise awareness among professionals to ensure that the right to play for all children is assured.
- [Learning Through Play in the Early Years](#)
- [Early Years Matter](#)
- [Learning and developing through play](#)
- [Royal National Institute for the Blind \(RNIB\) Learning through play in the early years](#) (has a lot of good ideas for easy and cheap-to-make toys)
- [I want to play too – inclusive play and leisure for children and young people](#)
- [Sensory play ideas for children](#)
- [Sense Play Toolkits](#)
- [Toys to make from everyday items](#)
- [Everyday items make the best toddler toys](#)

## Handout 5. Brain architecture

You can access more information and resources on brain architecture, building serve and return and effects of neglect by following these links.

- [Brain architecture](#)
- [5 steps for building serve and return](#)
- [Neglect](#)
- [Toxic stress](#)
- [The importance of early bonding on the long-term mental health and resilience of children](#)
- [The effects of stress in early childhood](#)