

Monitoring children's development in primary care services: moving from a focus on child deficits to family-centred participatory support

Report of a virtual technical meeting
9 – 10 June 2020



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Acronyms

CST	Caregiver Skills Training
GMCD	Guide for Monitoring Child Development
GSED	Global Scale for Early Development
IQ	Intelligence quotient
MCA	Department of Maternal, Newborn, Child and Adolescent Health and Ageing
MhGAP	Mental Health Global Action Programme
MSD	Department of Mental Health and Substance Abuse
NCD	Department of Noncommunicable Diseases
SDH	Department of Social Determinants of Health
UNICEF	United Nations Children’s Fund
UK	United Kingdom
USA	United States of America
USAID	United States Agency for International Development
WHO	World Health Organization

Executive summary

Globally, at least one in six children experience a developmental difficulty. However, developmental screening and monitoring are seldom supported by accessible, evidence-based assessments and interventions or effective referral pathways. Primary care services to identify and monitor children at risk of developmental delays and to support them and their families are the first step in building comprehensive services.

Currently there is no generalizable guidance on best practice approaches for monitoring children's development in primary care services, despite recommendations for this by professional associations, and the use of developmental milestones in some child health services and in national norms and standards.

WHO's MCA convened a virtual meeting from 9 – 10 June 2020 to discuss a way forward. The aim was to agree on how best to monitor children 0 - 3 years of age for risk of developmental delay, disorder or disability in primary care services, considering factors at the level of the child, the family and the community.

After discussing the content of literature reviews, presentations and discussions, attention shifted from a narrow focus on developmental monitoring to a broader inclusive approach of psychosocial support, building on a strong provider-caregiver relationship. Conclusions included:

- Given the wide variation in the way children develop and the broad range of influences on individual children's developmental trajectories, focusing on milestones alone is insufficient to detect children who are at risk of sub-optimal development.
- Many factors have a direct impact on early childhood development at the level of the family, community and the child. These factors should be an integral part of developmental counselling and monitoring in primary care services. Attention to caregiver mental health is essential.
- Multidomain developmental assessments are not routinely indicated for all children. However, they should be available for children who have clear signs of developmental delay or whose caregivers have serious concerns about their child's development.
- Cerebral palsy, vision and hearing difficulties are causes of developmental delay whose early manifestations are often detected late. These conditions require careful observations and screening in early childhood as part of universal support for early childhood development.
- Terminology needs to be consistent to advance on implementation. The word "screening" is poorly suited to describe assessment of children's development trajectories. In contrast, "monitoring" implies ongoing observation and adjustment, through information, counselling and support provided to caregivers and families.
- Services to support early childhood development must be organized according to the continuum of care, with developmental counselling and monitoring for all families and children as the basis for identifying those who require more intensive follow-up or indicated services.
- The momentum for integration of developmental monitoring and counselling in primary care services is strong, and therefore a unique opportunity exists for providing countries with the best possible guidance. The meeting laid out parameters for such guidance.

WHO, in collaboration with UNICEF and other partners, will take forward the conclusions in existing and future efforts to strengthen support for children's healthy growth and development.

Background

Globally, at least one in six children experience a developmental difficulty. However, developmental screening and monitoring are seldom supported by accessible, evidence-based assessments and interventions or effective referral pathways. Only about 60% of developmental difficulties are detected early enough for children to benefit from interventions, if they are available. Primary care services to identify and monitor children at risk of developmental delays and to support them and their families are the first step in building comprehensive services.

The *Nurturing care framework (1)* calls for every child to receive nurturing care and all caregivers to be supported to provide nurturing care within enabling environments of policies and interventions that protect, promote and support families and children. The Lancet series *Advancing early childhood development: from science to scale (2)* and WHO guidelines, including *Improving early childhood development (3)*, provide evidence in support of the *Framework*.

Nurses, doctors, other health professionals and community health workers providing primary health care play an important role in supporting nurturing care for early childhood development. As countries strengthen existing service platforms to integrate interventions for responsive caregiving and opportunities for early learning, there is increasing interest in early alerts to respond to children at risk of developmental delay or experiencing developmental difficulties. Currently there is no generalizable guidance on best practice approaches for monitoring children's development in primary care services, despite recommendations for this by professional associations and the use of developmental milestones in some child health services and in national norms and standards.

WHO's MCA convened a virtual meeting from 9 – 10 June 2020 to discuss primary care monitoring of children's development, with attention to the child's circumstances as well as developmental progress.

Objectives of the meeting

The aim of the virtual meeting was to discuss and agree on how best to monitor children 0 - 3 years of age for risk of developmental delay, disorder or disability in primary care services, considering factors at the level of the child, the family and the community. Specific questions posed included:

- i. What are the scientific, clinical and pragmatic merits of monitoring young children's development?
- ii. Which individual, family and community risk factors should be monitored because they signal potential threats to young children's healthy growth and development?
- iii. What is the strength of caregiver concerns and caregiver reporting to identify children with developmental difficulties?
- iv. Taking consideration of the above, what are recommendations regarding monitoring of sub-optimal development in children less than 3 years of age by front-line workers?
 - What are suggested timings for monitoring these different indices?
 - Who will conduct the monitoring; how will they be trained?
 - What actions can different cadres take based on the monitoring?
 - What is the potential of early intervention by front-line workers, and for which families and children can front-line workers apply early intervention?
 - When is more in-depth individual assessment of development recommended and by whom should it be conducted? What services need to be put in place for needed interventions?
- v. What would a typical record or counselling guidance look like to support developmental monitoring and developmental counselling?

Expected outcomes

The expected outcomes from the virtual meeting were:

- Consensus on terminology, including definitions of monitoring, screening and surveillance of early childhood development.
- Agreement on individual, family and community factors that influence early childhood development and should be borne in mind when monitoring development of individual children.
- Identification of basic requirements for preparing primary care workers to monitor early childhood development effectively and take follow-up action.
- Agreement on how to incorporate support to families and caregivers of children at risk or with signs of developmental delay, in primary care services or referral to specialized services.

Methodology

A Steering Group of independent experts and WHO and United Nations Children's Fund (UNICEF) staff was formed by MCA in October 2019 to conceptualize the meeting and formulate the questions to be addressed. A protocol for collecting background information was developed, and two reviews were commissioned.

First, a literature review focused on risks to development and best practices for monitoring young children's development by primary care workers. Second, a desk review of a sample of home-based records and counselling cards from countries in different regions aimed at identifying communalities and differences in approaches used for developmental counselling and monitoring.

A total of 77 participants registered for the virtual meeting which took place on 9 – 10 June 2020 (see **Annex 1** for List of participants). At any one time, approximately 70 participants joined in the discussions. They represented academic institutions, governmental and nongovernmental organizations and United Nations agencies from all regions.

The two reviews were presented during the meeting:

- 1. Detecting children aged 0 - 3 years at risk of sub-optimal development during routine primary health care: best practice guidance for policy-makers and programme managers**, by Xanthe Hunt and Mark Tomlinson, Institute for Life Course Health Research, Stellenbosch, South Africa

This review addressed the question, "What are recommended approaches for detecting risk of sub-optimal development in children 0 – 3 years of age by primary health care workers?" It considered systematic review papers published since 2017, as well as papers that the Steering Group deemed important to include. The date of 2017 was chosen to include papers published since the third Lancet series on early childhood development (2). Issues identified in the review included:

- Risks to early childhood development should be considered in terms of children's developmental progress as well as at the level of the caregiver, family and community.
- More attention should be paid to the social determinants of health, including poverty and food insecurity, as this provides important information on the environment of the child.
- Milestone-type assessments appear to be supported in many of the recent papers reviewed, with a few papers suggesting pared-down lists or "red-flag" approaches.
- Maternal mental health assessments can be implemented feasibly by trained non-specialist health workers, but it is not clear what care or referral to supportive services could be provided in primary care.
- Too few papers were identified to draw a conclusion on whether screening for violence and abuse can be integrated into routine services.
- Certain subpopulations of caregivers, defined by risks such as HIV exposure or very young mothers, may be most in need of ongoing routine monitoring in primary care settings as their children may face additional vulnerabilities.
- Effective implementation of developmental monitoring requires adequate training of primary care staff, supervision and monitoring of implementation quality, explication of referral pathways, and contextualisation of assessments.

- 2. Monitoring children's development and parenting advice in countries: an analysis of a sample of home-based records**, by Kid Kohl and Bettina Schwethelm, WHO consultants, Geneva.

The aim of this review was to outline approaches used in countries for monitoring children's development and providing parental advice on early childhood development. The definition of a home-based record is a health document used to record the history of health services received by an

individual, in this case the mother and child. Issues identified in the review included:

- Many countries use home-based records in routine primary health care services.
- Some content areas are common across the records examined: growth monitoring, child vaccination, breastfeeding and nutrition, and developmental milestones. However, details differ between countries.
- Variation was found for health screenings, risk factors (including social determinants), milestone monitoring and parenting advice.
- Challenges in the implementation of home-based records include anticipated literacy of caregivers and cost of producing records.
- Global guidance on minimum evidence-based content of home-based records for monitoring children's development and parenting advice to support early childhood development would strengthen the potential of these records to improve child health and development and caregiver support.

Summaries of the background documents are in **Annex 2**.

In addition to the two reviews, a background paper proposed definitions of commonly-used terms from various sources for developmental delays; developmental screening; secondary/selective developmental screening; developmental assessment/evaluation; developmental surveillance; developmental monitoring; and developmental milestones.

Information was also provided through presentations on:

- Children with developmental delays, disorders and/or disabilities: building a continuum of care for early interventions;
- Early detection and early intervention for children at risk of neglect or maltreatment;
- Global recommendations and guidance to strengthen the role of home-based records: Strengthening implementation of home-based records.

Three panels allowed discussants to share viewpoints and experiences, as a basis for further discussion in plenary, and a fourth provided reflections on the proceedings.

Summaries of the presentations and panels are in **Annex 3**, and the agenda is in **Annex 4**.

Summary of discussions

Within the broad aims of the meeting, discussion took place on a range of issues. A summary of participant inputs is provided by key themes.

Framing monitoring approaches for early childhood development

There are four main approaches to assessment that are relevant for early childhood development:

- primary care monitoring, in order to detect risk factors or problems, provide extra support to caregivers and the child, and refer as appropriate;
- clinical assessment of the child's development, in order to diagnose disorders and intervene;
- programme evaluation, to evaluate progress in implementation of interventions, the quality of services and their outcomes;
- population monitoring to determine what proportion of children are not developing well, which can be used for advocacy, policy development and strengthening of accountability of services.

The meeting was convened to discuss primary care monitoring of children's development, with attention to the child's circumstances as well as developmental progress. Monitoring involves observation of the parent and child, parental report and the use of checklists. Effective monitoring should result in extra support for families and young children who experience risks to their development as well as referral to a trained professional for assessment and an intervention plan for children with signs of developmental delay.

Terminology

A variety of terms, approaches and methods are in use to assess children's development, and consistent terminology is important to guide appropriate responses. (See **Annex 5** for a glossary of terms.) Universal agreement on definitions does not exist, but participants generally agreed on the following ones.

Screening refers to a brief one-off assessment of all or specifically targeted children. A 'screen' is used to detect problems. 'Screening', a term borrowed from medicine, implies looking for the presence of a disease or other unwanted condition that can be treated. Screening builds on specific tests that result in a 'yes'/'no' answer and for which a treatment is available. Screening tests must have high sensitivity and specificity to ensure that they are cost-effective. Specific criteria for screening were defined by Wilson and Jungner in 1968 (4) and have since been refined. Examples of screening include genetic testing during pregnancy, tests of vision and hearing, and metabolic or hormonal testing in the neonatal period. However, the word screening is not appropriate for monitoring of children's overall development trajectories as these are complex, and there is wide variation in normal development between children.

Developmental monitoring aims to keep track of, and support, each child's development. It differs from screening, which has a predetermined time frame, and which aims to detect aberrations. Developmental monitoring enables the child's healthy growth and development to be tracked, in collaboration with the family, and supports the provision of stimulating, nurturing care in the child's daily life. Monitoring includes risk factors that may be present in the life of the family and how the family is coping with these risks. During monitoring, families can be provided with information about the rights of children and community-based resources to support families. Approaches for monitoring children's individual development are recommended as part of the *Nurturing care framework*.

Developmental surveillance is often used as a synonym for monitoring. However, this term can be associated with security and policing. It can also imply looking for something that has gone wrong or is about to go wrong. Therefore, the term 'monitoring' is preferred for the processes that can be supported in primary health care services to detect children at risk of sub-optimal development and to provide support.

Milestones indicate the developmental abilities that children are expected to acquire on average at a certain age, sometimes with a range. Some early milestones are important because they are precursors to more advanced ones. For example, sitting without support is a precursor to walking without assistance and independently. Attainment of milestones in early childhood usually follows a normal curve, with a few children performing at the low and high ends of the curve and most children somewhere in the middle. Typically, milestones for monitoring children's development are set at the 70th percentile, i.e. at which 70% of children achieve the milestone. In addition, some approaches use 'red flags', with milestone attainment set at the 90th or 99th percentile, meaning that a child who has not reached this milestone is at greater risk of sub-optimal development. Given that the pace of children's development varies greatly, and that there is usually a very wide age range for milestone attainment, the use of milestones alone may lead to the over- and under-identification of children with developmental difficulties.

Multidomain developmental assessment instruments are psychometrically constructed and organized evaluations of milestones achieved by children at a given time. Milestone items are usually organized into domains such as motor, cognitive, language, communication and so on, and grouped according to how well they measure the same domain. In this way, domain scores and a total score can be calculated. If the developmental assessment has been properly standardized, the scores indicate a child's position in relation to a large representative sample of normally developing children.

While the term screening is sometimes used in the literature, it was agreed that the term monitoring reflects more accurately the role of primary care providers as well as the process to be followed in primary care services to detect young children at risk of sub-optimal development and provide them and their families with the support they may need.

What should be monitored, when and by whom?

What should be monitored?

Children's development is affected by a broad range of individual, family and community factors that should be part of monitoring, including risks such as poverty and maternal depression, as well as strengths that contribute to resilience, such as strong family or community support. Effectively, environments are

often better predictors of long-term outcomes than individual assessments, but they are frequently excluded from approaches which focus only on children's development.

Discussion centred around the use of milestones, parental concerns, and the assessment of environmental risk factors that have been shown to be directly linked to children's development. Importantly, participants emphasized that developmental monitoring should always be accompanied by support and counselling.

Milestones are most commonly used for monitoring children's developmental progress, but they are insufficient when used in isolation. Their effectiveness depends on the percentile at which they are set for each age group, and their interpretation should differ. Based on the review of home-based records and counselling cards, there is great variation in the selection of milestones and the timing of their use. Some records position the attainment of milestones at a specific time point, e.g. 6 months, while others provide a time period, e.g. 4 - 6 months. There was some commonality in recommendations for when milestones should be monitored, around 6, 12 and 18 months.

Using a limited number of milestones set at high levels of sensitivity and specificity could increase early detection and well-targeted interventions. It could identify children who would benefit from a more intensive multidomain developmental assessment and facilitate referral to a skilled provider, while at the same time minimize unnecessary referral. The development of a pared-down checklist of universally applicable milestones, set at the 90th or 99th percentile of population achievement, would strengthen the quality of developmental monitoring in primary care services and should be a priority for research and future investment.

Parental or caregiver concern about a child's development is important, and when raised with a health worker or other care provider, should raise an alert. The caregiver spends much more time with the child than the health worker and can describe the behaviours and potential problems of the child much more accurately. A concerned caregiver is an important informant on a child's developmental progression and regression, and the primary provider of nurturing care. In addition, caregivers almost always desire the best for their child, and for their child to be well and healthy. For this to happen, primary care workers can help caregivers acquire developmental knowledge or "literacy" to know when

to be concerned and support their “capacity” for caregiving – which may be threatened by survival issues, mental health problems or other difficulties.

Screening for specific conditions

Screening for accurate vision and hearing in early childhood need to be better integrated into primary care services, alongside early detection of cerebral palsy. They, together with muscle tone and coordination, are essential functions that should be checked from birth. Similarly, there is a set of metabolic tests that are important in the neonatal period, such as screening for phenylketonuria. Vision and hearing would normally be assessed as per WHO recommendations, and selected metabolic screening tests carried out according to national policy. All infants should have access to hearing screening using a physiologic measure at no later than 1 month of age, and all infants should be screened at birth for eye and vision defects. Eye examination should be undertaken as early as possible, before two months of age, to detect ocular abnormality and particularly treatable causes for visual impairment, such as cataract. Primary care services have an important role in implementing these recommendations.

Identifying children at risk of abuse

For a variety of reasons, routine monitoring or screening for child abuse is not recommended according to WHO guidelines. However, the health care provider should be alert to signs that a child or caregiver might be exposed to abuse. These signs include regression on previously achieved skills or behaviours, unexplained injuries, poor caregiver-child interaction, or a negative caregiver perception of the child. In counselling on early childhood development, it is important to cover issues such as maternal mental health, poverty and ability to take care of the child (family support, maternal working). A home-based record might be a sensitive place to record information about substance abuse, intimate partner violence and similar topics. However, it can include information on prevention of abusive relations and where to seek help.

In conclusion, there was consensus about the importance of monitoring:

- **progression of the child’s development** over time, and in the interval between contacts with a skilled provider. Regression or stagnation should always raise an alert. When the child has acquired new interests and skills, it is a positive sign.
- **strengths of the child and the family** as well as strengths and opportunities within the community;
- **individual health-related and psychosocial risk factors** related to the child (pregnancy and birth complications, prematurity, infections, malnutrition, chronic illness or disability, temperament), and the caregiver (physical and mental health, teenage parenthood, education, socioeconomic status, intra-family conflict or violence);
- **community risks** (violence, poverty, environmental toxins, humanitarian crisis settings, lack of services and resources to support child development such as preschools, and services for disabilities).

When to monitor?

Participants concluded that developmental monitoring should be part of every contact that young children and their caregivers have with services. Monitoring should use a mixed approach of parental/caregiver concern, and a pared-down set of items related to strengths of the child and family. It should also include health-related and psychosocial risk factors and developmental milestones that indicate the child’s functioning and activities.

Multidomain assessment tools should not be used in a vacuum nor should they be applied for all children. More in-depth individual assessment should be recommended for children with signs of developmental delay or regression, or whose caregivers have a concern that cannot be addressed at primary care level. Children with certain high-risk characteristics (e.g. premature infants) should have developmental assessments at pre-defined times. Conducting such assessment should always be accompanied by caregiver inputs on the environment, including family strengths and risk factors, as an entry point to support any interventions required.¹

1. WHO and UNICEF are conducting an evidence review of available multidomain assessment tools. Based on the review, updated recommendations will become available on a small set of tools that are feasible for valid and reliable use by non-specialist providers, including in settings with limited resources.

Noting the need to avoid unnecessary referrals, the following criteria emerged for guiding the organization of services. They encompass follow-up at the level of primary care services and referral to a higher level when required:

- **children exposed to risk factors for developmental delay:** additional follow-up with developmental counselling and monitoring;
- **children who are not meeting all milestones for their age group:** additional follow-up with developmental counselling and monitoring;
- **children with signs of developmental delay or whose parents have a serious concern:** referral for developmental assessment by a higher-level skilled provider;
- **in all situations, build on strengths and family networks that exist or might be leveraged.**

For additional follow-up, some countries have established a home visiting programme with skilled professionals, who are able to provide comprehensive support to the family and arrange for referral to facility-based care and social services according to need.

Principles for moving forward

From a deficit model to family-centred participatory support

Primary care providers can play a critical role in providing caregivers with support for nurturing care and in the amelioration of developmental difficulties. They can also help to overcome stigma associated with disabilities in many communities and increase the access of children with development delays or disabilities (and their families) to adequate support services.

Supporting early childhood development calls for a partnership between caregivers and care providers, starting from pregnancy or even before. The longitudinal and cumulative nature of developmental monitoring enables primary care providers to know the child's and family's strengths and vulnerabilities over time; to watch, appreciate and support the child's development with the family, while also partnering to enhance strengths, address risk factors and provide additional support and specialized services when needed. It provides opportunities for anticipatory guidance, enables caregivers to strengthen their knowledge about how to support their child's growth and development and ask for advice when needed.

Monitoring children's development must be couched within support at the primary level of care and preferably during the same contact. It is the support system that allows for monitoring to be fully embedded and effective in services. A system of simply 'monitor and refer' is not efficient. The approach should be comparable to treating a minor health problem – a condition is not just diagnosed, but some basic help is given at the time and follow-up is arranged. Primary care workers should be able to observe caregiver-child interaction, be sensitive to 'common-sense' signs that can serve as alerts and offer basic suggestions for common concerns, e.g. to encourage more conversation and joint reading time when a child is slow in developing language skills.

Activities that can be completed with caregivers during counselling and monitoring for early childhood development in primary care services and for which tools are available include:

- orient the family as to what is implied by child development;
- elicit and attend to caregivers' concerns;
- ask open-ended questions to explore domains of a child's development, family functioning and needs;
- include child's health, functioning, activities and participation in family life, the nurturing care provided, and the family's functioning and needs;
- explore health-related and psychosocial developmental risks;
- learn about family strategies to cope with risk factors and the need for additional services;
- acknowledge and praise the family for the support it is already providing for the child;
- provide anticipatory guidance and information on how to support development;
- provide opportunities to model good practices in primary care clinics and waiting rooms.

During the consultation, the provider can carefully observe the interactions between the caregiver and child and pick up signals that indicate the strengths (or difficulties) in their relationship.

The WHO/UNICEF *Care for child development* package (5) is organized around the principles of informed watching, enjoying and supporting the child's development, with the family. It builds the capacity of primary care providers to partner with caregivers to enhance strengths, address risk factors, and provide additional individualized support and services when needed. **Figure 1**, based on the *Care for child development* materials, reflects participants' views on some of the observations a provider could carry out.

Figure 1. Observing caregiver-child interactions

Observing caregiver-child interactions

Observe the signs of responsive caregiving during the visit. *Tick the boxes that would be most feasible for providers of health and nutrition services to assess routinely.*

How does the caregiver show that he or she is aware of the child's movements?

Does the caregiver look at the child, shift positions, or move to respond to the child? Responsive caregivers are aware of the sounds and movements of their children. They follow the children's leads and interests. They are "in tune" with their children, even when they are engaged in another task, such as a discussion with the provider.

If the child fusses, how does the caregiver comfort the child and show love?

Does the caregiver look into the eyes of the child and talk softly? Does the caregiver hold the child closely and firmly, rather than roughly bounce the child or scold the child? Does the caregiver bring the child closer, or push the child away?

If the caregiver disapproves of what the child is doing, how does the caregiver correct the child?

How does the caregiver distract the child away from the unwanted activity or object? Does the caregiver reinforce the child's shift in behaviour with kind words or gestures? Does the caregiver scold or physically punish the child?

Does the child look at or reach for the caregiver?

All children—including children who are blind or have other difficulties—search for a response from their caregivers, visually or by touch or movement. Does the child avoid the eyes of the caregiver? When caregivers do not respond, their young children stop looking at them and often look to others, even strangers, for a response. This avoidance of the caregiver may be a *danger sign*. The caregiver may not be responding consistently with the child's attempts to reach out for care, attention, and affection.

From: WHO and UNICEF Care for Child Development (2012)

Entry points for system strengthening

Health and nutrition services provide excellent entry points for providing support to families of young children. Services for preventive or chronic care, growth monitoring and counselling, immunization and social services and well-child visits are natural fits for integrating developmental monitoring and counselling. These contacts are feasible, depending on the context. For example, asking a caregiver how she and her child are doing, observing the child and caregiver-child interaction, and giving information and support can be conducted before, during or after routine vaccination. However, contacts differ from large lines at clinics to individual appointments.

In some countries, a major barrier can be the time allocated or billable to insurance. Nevertheless, developmental counselling and monitoring should be fully integrated in essential interventions and protocols for primary health care.

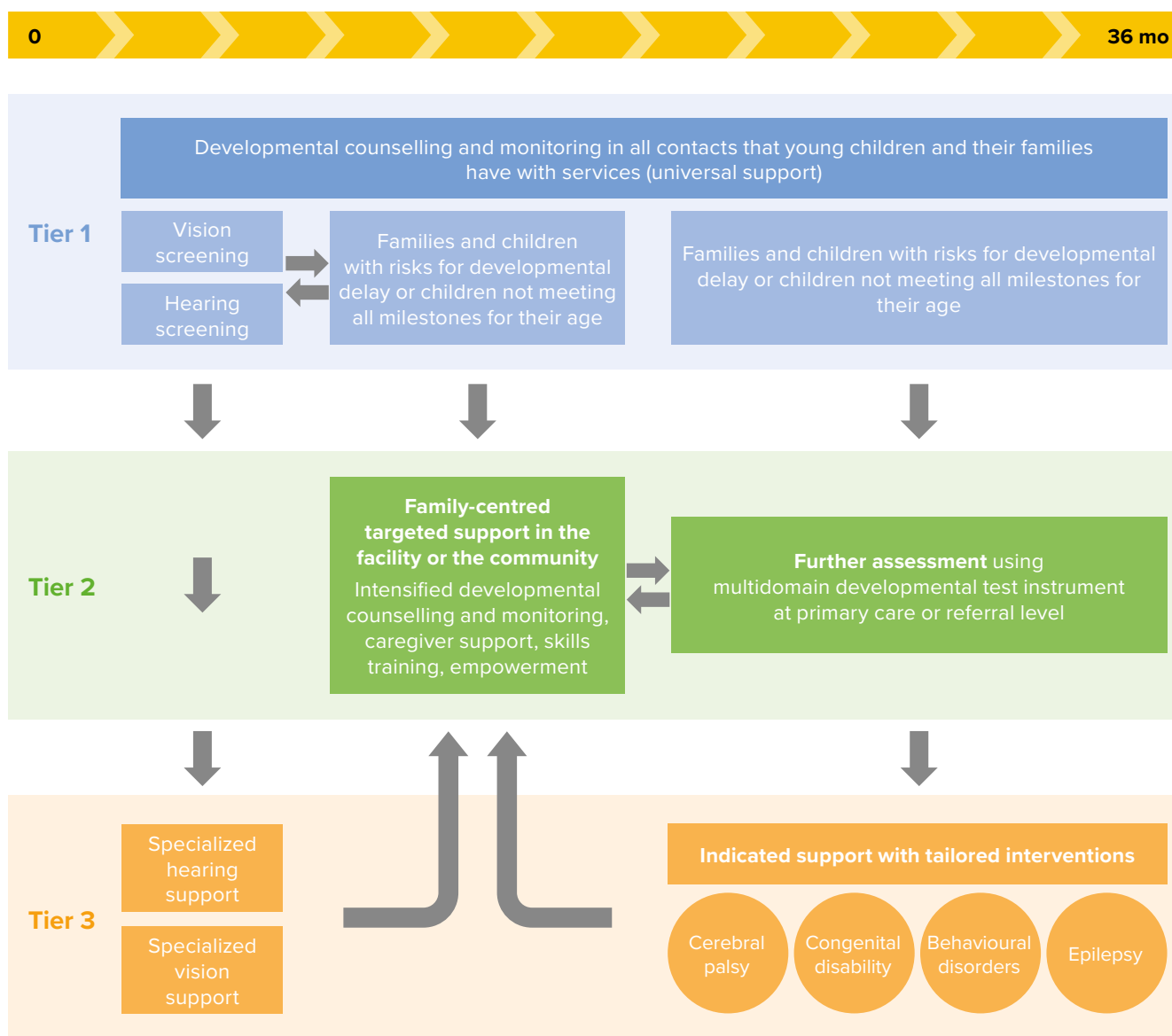
The Integrated Management of Childhood Illness approach can also be used as an entry point for counselling caregivers and monitoring children's development. The limitations for monitoring during a sick-child visit depend on the context, but an important opportunity could be missed by not using it. In some countries, materials already have been updated with guidance on developmental monitoring and counselling, including during follow-up visits.

Demand creation, including through the demonstration of quality services, has the potential to ensure that developmental counselling and monitoring is strengthened. One way to create demand is to orient caregivers around a home-based record with milestones and developmental messages.

Efforts to strengthen service provision need to be accompanied by appropriate indicators that can be incorporated in routine (health) information systems. This can include indicators for children identified in need of additional (or targeted) support in primary care services or referral for specialized care.

Figure 2 illustrates the continuum of care of universal, targeted and indicated support to cover the needs of all children and their families. All contacts that families and young children have with services, from pregnancy through the early years, can be used to provide universal support. This includes scheduled visits for immunization that are most commonly used by families of young children and generally have a high level of coverage, from birth through the first 2 years of a child's life, according to government policy.

Figure 2. Continuum of care of support



Source: adapted from UNICEF's early identification early intervention model presented at the meeting.

Health workforce capacities

Quality services to support child development are provided by staff who can take on primary responsibility for the child and family and consult with related disciplines about specific aspects of the child's or family's difficulties. This non-fragmented approach is referred to as transdisciplinary care. In most settings, providing such care requires re-orientation from traditional medical to biopsychosocial approaches. Staff require both competence and confidence. They should be able to address a range of concerns associated with children's development, for example, issues related to sleep and crying. Primary care workers, including community health workers, can fill this role provided they are well trained (including on communication and counselling), receive mentorship and have a clear referral link to more advanced care. Recognizing the variation in staffing and workloads of primary care facilities in different settings, services can be improved incrementally. Early childhood development should also be integrated into pre-service training curricula. There is need for more open source tools to build the capacities of multiple cadres of front-line workers and address health system requirements, considering a continuum from primary care services to additional and specialized support for children with developmental difficulties and their families.

The role of home-based records

Home-based records are widely used, increasingly to support early childhood development. They have the potential to include a wide range of issues related to early childhood development and go beyond a narrow focus on milestones. They are likely to generate the best results when used in partnership between a skilled care provider and a caregiver. Given the availability and interest of governments to use home-based records, and the recent WHO guideline (6) that supports their use, a clear opportunity exists for generic guidance to assist countries in identifying the best possible content, without overloading the card with information. Promoting the tool as a way of strengthening communication between the caregiver and the care provider is important. The use of digital home-based records as apps instead of print records deserves exploration. The format of home-based records in fragile settings where print copies may be lost also needs special consideration. The use of a traditional child necklace in India (7) to carry digital immunization records was cited. To strengthen the role of home-based records, participants called for more research, including on the selection of milestones that can serve best as alerts that a child is at risk of developmental delay.

Conclusions

During the meeting the attention shifted from a narrow focus on developmental monitoring to a broader inclusive approach of psychosocial support, building on a strong provider-caregiver relationship.

Primary care providers are well positioned as the first level of support for early childhood development. They should be provided with the skills to monitor and counsel during regular contacts of families and young children with services, with the possibility of referral when needed.

Given the wide variation in the way children develop and the broad range of influences on individual children's developmental trajectories, focusing on milestones alone is insufficient to detect children who are at risk of sub-optimal development. This approach can also lead to misclassification of the child's actual status, cause parental anxiety and unnecessary referral.

Many factors have a direct impact on early childhood development at the level of the family, community and the child. These factors should be an integral part of developmental counselling and monitoring in primary care services. Among these factors, caregiver concerns and a child's regression of a previously attained milestone must serve as clear alerts. Attention to caregiver mental health is also essential.

Multidomain developmental assessments are not routinely indicated for all children. However, they should be available for children who have clear signs of developmental delay or whose caregivers have serious concerns about their child's development.

Cerebral palsy, vision and hearing difficulties are causes of developmental delay whose early manifestations are often detected late. These conditions require careful observations and screening in early childhood as part of universal support for early childhood development. Specific timings for vision and hearing screening of all children may also be defined in national policy.

Terminology needs to be consistent to advance on implementation. The word "screening" is poorly suited to describe assessment of children's development trajectories. In contrast, "monitoring" implies ongoing observation and adjustment, through information, counselling and support provided to caregivers and families.

Services to support early childhood development should be organized according to the continuum of care, with developmental counselling and monitoring for all families and children as the basis for identifying those who require more intensive follow-up or indicated services.

Such a continuum of care calls for progressive systems with different cadres of workers and an appropriate skills mix. Primary care providers can be the cornerstone, but they must be skilled and supported to work with families and young children and facilitate home care practices that meet the core aspects of nurturing care. Home-based records are part of service provision in many countries and can be a useful tool to strengthen provider-caregiver interactions and support caregiver understanding of children's development and the important role of parents.

Finally, the momentum for integration of developmental monitoring and counselling in primary care services is strong, and therefore a unique opportunity exists for providing countries with the best possible guidance. The meeting laid out parameters for the development of such guidance.

Next steps

WHO will work with UNICEF and other partners to agree on consistent terminology in support of developmental monitoring and counselling. Forthcoming publications, such as the *Global report on disabilities* and the work on early identification and intervention for children with disabilities, coordinated jointly by UNICEF and WHO, are opportunities for promoting harmonized language.

WHO and UNICEF will take note of the outcomes of the meeting in formulating guidance for countries on the optimal design and use of home-based records. The review to provide the basis for this work is currently under way and will cover a wide spectrum of maternal, newborn and child health issues, including attention to nurturing care.

To meet the needs for further assessment in children with risks of sub-optimal development, WHO and UNICEF are conducting an evidence review and consultative process to come up with a short list of multidomain assessment tools that can be used in a reliable and valid manner by non-specialist providers who have been trained in their use. These organizations are also working together to develop a practice guide for strengthening health and nutrition services to more comprehensively support nurturing care, and this guidance will include a section on monitoring.

While further evidence is being generated, an evidence-based template with questions and alerts is proposed in **Figure 3**, which reflects the meetings' discussions, for consideration by programme staff who are seeking to strengthen support for early childhood development in primary care services.

As part of global child health programming, WHO and UNICEF will integrate guidance on developmental monitoring and counselling in service packages for primary care workers and promote an approach of family-centred care based on the *Nurturing care framework*.

Attention will be given to health system requirements including the capacities of the workforce, the need for a pyramid of services with different levels and intensities of care, and the use of home-based records to strengthen caregiver-provider interaction and improve caregiver literacy around children's development.

The conclusions of the meeting can inform advocacy to strengthen country programmes and services, and all partners have a role to play in supporting countries to facilitate their implementation.

Figure 3. Skills to use in monitoring children’s development and addressing developmental difficulties

Orient the caregiver. “Just as it is important to follow [Child’s Name]’s physical health and growth, it is important to follow and support development. A child’s brain develops most rapidly during the early years. It is useful to monitor development and to see if there are any areas that need extra support. By development I mean, learning, communicating, understanding, relating to people, moving body, using hands and fingers, and also hearing and vision. Let me ask you about how [Child’s Name]’s is developing in all of these areas. Please give me examples of what she does in her daily life.”

- Address all caregiver concerns
- Assess and address child’s health problems (eg: growth, nutrition, perinatal problems, chronic illness) using history, comprehensive physical and neurological exam, labs when needed
- Assess and address nurturing care, opportunities for learning, psychosocial risk and protective factors (Questions 8, 9, 10)
- Assess all domains of development using appropriately standardized, reliable, validated tool
- Follow closely (e.g. see back in one month)
- Refer for consultations and/or services when needed
- Conduct valid hearing test and vision test as needed

1. Caregiver’s concerns.
 “I’d like to first ask you, do you have any concerns about [child’s name]’s development in any of these areas?”

	WHAT TO EXPECT BY COMPLETED AGE			
	6 MONTHS	12 MONTHS	18 MONTHS	30 MONTHS
<p>2. Expressive language. “How does your child let you know when she wants something? What kind of sounds, gestures words does she use?”</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Laughs aloud <input type="checkbox"/> Vocalizes vowels (“aa, uu”) 	<ul style="list-style-type: none"> <input type="checkbox"/> Babbles by repeating many syllables <input type="checkbox"/> Has one meaningful word <input type="checkbox"/> Uses arm or hand to point to people or objects 	<ul style="list-style-type: none"> <input type="checkbox"/> Uses at least 2 meaningful words <input type="checkbox"/> Uses index finger to point <input type="checkbox"/> Caregivers understand some of child’s communication 	<ul style="list-style-type: none"> <input type="checkbox"/> Uses sentences with 3 words to communicate <input type="checkbox"/> Uses pronouns (I, me, you) <input type="checkbox"/> Caregivers understand most of child’s communication
<p>3. Receptive language. “How does she show you that she understands when you talk to her? For example, what does she do when you say: Where’s daddy? Where’s ball? Come here!”</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Responds by making sounds when caregivers talk 	<ul style="list-style-type: none"> <input type="checkbox"/> Understands names of familiar people (mummy, daddy) <input type="checkbox"/> Understands verbs/action words (come, take) <input type="checkbox"/> Understands names of objects (ball, toy) 	<ul style="list-style-type: none"> <input type="checkbox"/> Waves “bye” or uses other common gesture in response to command <input type="checkbox"/> Understands one simple command (bring shoes) 	<ul style="list-style-type: none"> <input type="checkbox"/> Understands one preposition (other than “in”) such as “under” or “on top”
<p>4a. Gross (large) movements. “Tell me about her movement, like holding and raising her head, sitting, walking.”</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Lifts head 90° (prone) <input type="checkbox"/> Sits with support <input type="checkbox"/> When held erect, straightens legs, pushes against object rather than bending legs 	<ul style="list-style-type: none"> <input type="checkbox"/> Sits steady without support <input type="checkbox"/> Pulls to stand holding on to objects <input type="checkbox"/> Stands alone momentarily <input type="checkbox"/> Walks holding onto objects 	<ul style="list-style-type: none"> <input type="checkbox"/> Walks alone <input type="checkbox"/> Kicks ball or other object 	<ul style="list-style-type: none"> <input type="checkbox"/> Climbs, jumps

	WHAT TO EXPECT BY COMPLETED AGE			
	6 MONTHS	12 MONTHS	18 MONTHS	30 MONTHS
<p>4b. Fine movements. “How does she use her hands and fingers, like holding objects?”</p>	<input type="checkbox"/> Reaches towards objects with hands <input type="checkbox"/> Holds, handles toys/objects	<input type="checkbox"/> Picks up small objects using pincer (thumb and index finger) only	<input type="checkbox"/> Holds pencil or stick (in any way) and scribbles on paper or on ground/floor	<input type="checkbox"/> Understands one preposition (other than “in”) such as “under” or “on top”
<p>5. Relating. “How does your child relate to people she knows? How does she show interest in them?” What does she do to engage them? How is her eye contact? <i>Wait for caregiver to respond, then ask:</i> “How does she relate to strangers or show that she knows they are strangers?”</p>	<input type="checkbox"/> Has prolonged, meaningful eye contact <input type="checkbox"/> Shows preference, recognition and desire to engage with caregivers by reaching, smiling, inspecting their faces	<input type="checkbox"/> Spontaneously seeks to share enjoyment and interest with others (cuddles caregiver, kisses, inspects toy together) <input type="checkbox"/> Shows recognition of stranger (turn away, stare)	<input type="checkbox"/> Initiates specific interactions with people <input type="checkbox"/> Imitates others’ behaviors (waving back, scribbling, washing hands, stacking clothes in imitation)	<input type="checkbox"/> Initiates increasingly warm and varied interactions with people
<p>6. Play activities. “Tell me about your child’s play. How does she play with people, with objects or toys?” Ask if needed: “What playthings or toys does she have, how does she play with them?”</p>	<input type="checkbox"/> Makes sounds in response to face-to-face play <input type="checkbox"/> Brings toys/objects to mouth	<input type="checkbox"/> Initiates game “peek-a-boo” <input type="checkbox"/> Inspects toys/objects with curiosity <input type="checkbox"/> Imitates gestures during play (clapping hands, make face)	<input type="checkbox"/> Inspects how toys/objects work (how doll moves, bells ring) <input type="checkbox"/> Has simple imaginary play like feeding doll, driving cars	<input type="checkbox"/> Involves others in play
<p>7. Self-help activities. “What does she do for herself, like feeding herself?” (Ages of attainment of self-help skills may vary across cultures)</p>	<input type="checkbox"/> Children in this age range may not be expected to attain self-help milestones	<input type="checkbox"/> Uses fingers to feed herself (knows it is food and eats)	<input type="checkbox"/> May use one feeding utensil <input type="checkbox"/> Drinks from cup	<input type="checkbox"/> Takes a piece of clothing off <input type="checkbox"/> Washes hands with assistance
<p>8. Nurturing care environment. “Thank you for telling me so much about (child name) development, you know her so well. Now please tell me about her daily life. What do you and your family do at home, in your daily life to help her develop, learn, communicate?” <i>Listen to what the caregiver is telling you. Prompt by asking: “What do other family members and friends do with her?” Support caregivers by acknowledging and praising all their efforts. Provide ideas from WHO/UNICEF Care for Child Development, or the “GMCD Support Component” or other interventions when necessary.</i></p>				
<p>9. Developmental risks. “Sometimes caregivers may have a lot going on. For example, they may feel overwhelmed, stressed or depressed, there may be financial problems or illness in the family, and caregivers may find it hard to support their child’s development. Are there such or other difficulties in your family situation?” <i>Listen with empathy, identify and help address psychosocial risk factors.</i></p>				
<p>10. Planning for interventions and follow-up. “What are some ideas or plans you have to support (child’s name) development despite these difficulties? At this early age when development is so important, what could you, your family, friends and community do to help her develop?” <i>Support caregivers’ efforts. If caregivers do not have ideas or plans, tell them you would like to talk further with them about these. Provide your feedback on development, make referrals and plan follow-up together with the caregiver.</i></p>				

***Adapted from the International Guide for Monitoring Child Development (GMCD) Training Package with permission from its authors. The milestones provided here were attained by at least 85% of healthy children in the international GMCD Study standardization sample at the given ages.**

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Annexes

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ANNEX 2.

Executive summaries of reviews

1. A narrative review concerning the use of approaches to detect children 0 – 3 at risk of sub-optimal development: best practice guidance for policy-makers and programme managers

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Background

Opportunities exist in primary care for the early detection of developmental and behavioural problems in children between the ages of 0 and 3 years. However, current evidence suggests that there is a large detection gap. A common demand in countries is for guidance regarding best practices in the routine monitoring of children's development at the individual level, by primary care workers. Currently, there is lack of clarity about which approaches to routine monitoring – particularly as conducted by trained non-professional front-line workers – are most effective at detecting children who require additional services.

However, only certain categories of approaches to developmental monitoring and detecting children at risk of poor development are widespread. For instance, the use of developmental milestones charts to assess children's progress against a set of predetermined age-related (50th percentile) achievements are ubiquitous. There are other approaches to detecting children at risk, but the presence of these are not widely established in primary care settings, potentially leading to missed opportunities for preventive care. This document maps current approaches to detecting children aged 0 – 3 at risk of suboptimal development and highlights lessons countries might use to inform their decision-making about which approaches are feasible and useful for implementation at primary care in their context.

The WHO Steering Group defined the relevant bodies of literature to be reviewed. These *a priori* categories reflect the broad conceptual 'buckets' into which child development, and known threats to it, can be assessed in public health, and formed the basis of the search strategy for the review:

1. individual level: milestones and developmental assessments;

2. individual level: other risk factors and vulnerabilities;

3. family- and household-level risks (maternal mental health and caregiving behaviour; violence and abuse; other vulnerabilities and adversities).

Methods and findings

Evidence generation for the present work drew on two sources: a large systematic search of the literature (mostly reviews, since 2017) on child developmental monitoring and the detection of children at risk, and the elicitation of seminal papers from the Steering Group. There were 739 papers detected in the milestones and developmental assessments search; 4178 papers were detected in the individual level vulnerabilities search; 971 papers in the maternal mental health and caregiving behaviour search; 1508 papers in the violence and abuse search; and 1208 in the vulnerability and adversity search. The submissions from the working group included six papers concerning milestones and developmental assessment, one concerning vulnerability and adversity, and one pertaining to individual level vulnerabilities.

Milestones and developmental assessments

There appears to be variability in what milestones, and within milestones, which specific items, predict. For instance, regarding intelligence quotient (IQ), milestone attainment at 4, 8 and 12 months predicted only a small part of IQ variance at age 5 to 6 years in a study by Peyre and colleagues (2017). However, milestone attainment at 24 months predicted a substantial part of the later IQ variance, and some domains (language skills) were most predictive of later IQ (and disability and giftedness). Milestones approaches and other standardized developmental screening tools are commonly used to assess

neurodevelopmental status and detect probable developmental delay. All tools were either administered to parents by primary health care or education workers, or completed by caregivers directly, and so have good applicability to front-line settings, given their relative ease of completion. However, quality oversight is imperative. Children's performance depends on their environment, and so there is a need to develop local reference charts and to consider the child's environment when assessing milestones. Normative data can help clinicians set realistic expectations for milestone attainment. Milestones-type assessments may not be as sensitive to certain types of delays compared to others, and when administered among linguistic groups among whom the tool was not initially developed, developmental assessments may not be valid. There is the possibility of testing milestones charts where a reduced number of items (for instance, as in the Cambodia cDMAT study [Ngoun and colleagues, 2020]) are used to identify children for further developmental assessment. These include "red flag" lists, which define either the 90th or 99th percentile, and other warning signs, which are used to detect only the most likely cases of delay. There appears to be a lack of thoroughly validated non-English language assessment tools. Developmental monitoring does commonly not, but should, include assessment of behavioural risk and social determinants of health (including what is reviewed below as family- and household-level risk) to contextualize results.

Individual level vulnerabilities

Reducing the number of items in autism screening instruments could assist with the integration of assessment into primary care contexts, and help to speed up the assessment process, making it simpler for service providers with limited experience to implement. Children born prematurely and in unfavourable environmental and social conditions may be more vulnerable to developmental problems at a very early age and so should be singled out as a special population for evaluation and follow-up of development. Certain subpopulations of children, including those affected by HIV and those born to adolescent parents, require special consideration in front-line contexts, and where these circumstances are present, mothers and children should be eligible for targeted support. In-depth and systematic cultural and contextual adaptations need to be made in order for screening efforts for autism to be valid. Implementation data regarding the process of rolling out screening for developmental conditions such as autism are inconsistently reported in the literature.

Maternal mental health and caregiving behaviour

The identification of women with postnatal depression is imperative not only because it provides an opportunity to support better mental health for women, but also because maternal depression places children at risk of poor development. A wide variety of personnel have been documented to successfully implement maternal mental health screening. However, the adequate training of implementers on the relevance and need for culturally safe assessments, being cautious in selecting screening tools and not relying on a single measure, and ensuring that reporting the results of a screener to women uses cultural explanations that avoid medicalized labelling, are essential for optimal implementation. There is the possibility of testing tools where a reduced number of items are used to identify women for further screening. There appears to be a gap in the assessment of caregiving behaviour and parental coping in front-line settings.

Violence and abuse

A majority of screening tools for child abuse are utilized in emergency care settings by paediatricians and other professional health care workers. Universal screening is not yet recommended for domestic violence. However, guidelines recommend that staff ask service users whether they have experienced domestic violence, whether or not indicators of violence and abuse are present, in the following populations: women with mental health symptoms or disorders; women attending for antenatal care; women experiencing substance abuse problems; and women presenting for sexual health or HIV testing. A gap exists in the literature regarding a potential tool to assess all forms of child abuse and neglect at the point of care in the health care delivery system.

Vulnerability and adversity

There is debate in the literature regarding whether routine screening for adverse childhood experiences should be carried out in paediatric populations. If screening is to be undertaken, to be feasible for paediatric practitioners in most types of practice, screening instruments should be cost-effective (free or a one-time low fee), have a relatively short administration time (no longer than 10 minutes or 30 items), and require no training or minimal training to administer. It is unclear whether there is evidence on which adverse childhood experiences merit screening in primary health care paediatric settings.

Discussion points

The use of milestones-type assessments appears to be supported in many of the recent papers reviewed, with a few providing evidencing for using pared-down lists of milestones which – if used in routine monitoring – would detect probable disability by referring to the 90th or 99th percentile, and as such not overload health care systems with unnecessary referrals. Another option noted in one paper is the utilization of “red flags” checklists, possibly for use where resources for referral are scarcest.

Maternal mental health assessments could be implemented universally given the evidence that non-professional health care workers can successfully implement evidence-based assessments of maternal mental health. Further, some of the recent reviews analysed note that there are pared-down, few-item options which show good discriminant validity. Nonetheless, questions of referral remain, and it is not always clear in low- and middle-income countries what detection of maternal mental health problems might lead to in terms of referral to supportive services.

The acceptability, feasibility and utility of violence and abuse assessments in primary care settings show conflicting evidence. On the basis of this and the low number of reviews included in this analysis, it is not possible to draw conclusions about whether such domains should be monitored or assessed routinely.

More attention to the social determinants of health, including food insecurity, is being paid, with papers from a variety of domains noting the relevance of using this important contextual information to frame assessment findings. However, based on this review, it is unclear how these aspects of a caregiver and child’s life might be assessed in primary care settings, and the referral pathways are not readily apparent.

Based on past evidence syntheses documents summarized here, certain subpopulations of caregivers, defined by risk such as HIV exposure or adolescent age, may be most in need of ongoing routine monitoring in primary care settings as their children face additional vulnerabilities. Finally, effective implementation in diverse contexts relies heavily on adequate training of primary care staff, supervision and monitoring of implementation quality, explication of referral pathways, and contextualisation of any assessment used, as noted in many of the papers reviewed.

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2. Monitoring children's development and parenting advice in countries: an analysis of a sample of home-based records

Kid Kohl and Bettina Schwethelm, WHO consultants

Background

Since the launch of the *Nurturing care framework* in 2018, there has been a keen interest among governments and partners to strengthen the role of the health sector, alongside other sectors, to support early childhood development. As countries are strengthening service packages to include attention to responsive caregiving and opportunities for early learning, a common demand arises for guidance on monitoring individual children's development. Developmental monitoring aims to keep track of, and to support, each child's development. However, there are currently no unified global recommendations for monitoring children's individual development, nor is there a standardized lexicon to describe related processes and tools. WHO is currently looking at the evidence in the literature and practice in countries. For the latter, a review of home-based records² was conducted to understand current approaches used in countries to monitor early childhood development and provide parental advice. The analysis of home-based records was complemented with information from a selection of country counselling cards and recommendations from selected national paediatric associations.

Methods

We first performed a targeted quantitative analysis of a convenience sample of 46 home-based records, which included an early childhood development component, across all six WHO Regions. In this analysis, we reviewed whether records included content related to: i) developmental milestones; ii) parenting advice; iii) child health danger signs; and iv) family and household risk factors (such as poor maternal mental health, teenage mother, violence in the home or low birth weight).

In a second step, we conducted a more detailed quantitative and qualitative analysis of a sub-selection of 12³ home-based records across the six WHO Regions. This analysis focused on: i) individual and family-related factors that affect early childhood development; ii) recording of developmental milestones; and iii) parenting advice given for children's development and for provision of a safe and secure environment.

Results

Home-based records are very diverse. Of the 46 records reviewed, 15 included maternal and child health content, while 31 focused on child health only. Records covered variable age ranges for the child from 0 - 2.5 years up to 0 - 20 years, with the most common age range being 0 - 5 years. The 46 health records also varied substantially in their length. Some were four to six pages long, while others consisted of up to 200 pages. Long records usually included multiple pages of health forms (e.g. well child, sick child, notes for parents or health workers) as well as extensive parenting advice (e.g. on nutrition or security and safety issues). Child health components that were well covered across all records were growth monitoring, vaccination and breastfeeding. Child development milestones were assessed in some form in 90% of the records, parenting advice related to components of nurturing care was also commonly addressed (89%), and danger signs related to child illnesses were described in 70% of the records. However, family and household risk factors for early childhood development were mentioned in less than one half (43%) of the records, and referral to specific health centres, helplines or additional resources were provided in less than one quarter (24%) of the records.

2. A home-based record is a health document used to record the history of health services received by an individual that is usually kept at home.

3. Australia, Costa Rica, Peru, India, Northern Macedonia, Oman, South Africa, Thailand, Tunisia, Uganda, UK, Vietnam.

The in-depth analysis of 12 home-based records reviewed what kind of family and household risk factors were addressed. Most commonly (42%), issues around substance use (mostly alcohol or smoking) were assessed. Other risk factors were the mother's age (young or old) (33%), employment or education of the parents (33%), maternal mental health (25%) or previous illness of the mother (25%). Mechanisms for financial support were mentioned in three of the 12 records. Two records mentioned risk factors such as violence, HIV, social deprivation, parent/mother absent or ill, and one record mentioned social deprivation. Overall, records focused more on the health and well-being of the child than that of the mother. In the five mother and child health records, most maternal content focused on the pregnancy phase and much less on postpartum care of the mother. In terms of newborn health, most records focused on assessing birth complications, such as prematurity and low birth weight, and initiating breastfeeding, while screenings for APGAR, hearing or movement were less common. Related to child health, the most common components across records were vaccination, growth monitoring, breastfeeding and complementary food. Nine records included parenting advice for early learning and play with the child, and 10 records assessed developmental milestones. However, when we reviewed the parenting advice and milestones in more detail, we found substantial variation between records. For example, there was variation in "how", "when" and "which" milestones were assessed. Some records recorded milestones until the age of 2 years, others until 6. Some records indicated seven or eight assessments while others had up to 15 to 17 for the same age range. On some records, milestones seemed to be assessed mainly by parents, while on others it was carried out by health workers. About 50% of the records provided alerts if a certain milestone was not reached by a certain time, and recommended caregivers to seek support from a health worker.

Parenting advice provided on home-based records covered a large spectrum of information including feeding and nutrition, growth monitoring, hygiene, care of the sick child and child stimulation. We focused specifically on: i) responsive caregiving; ii) early learning; and iii) safety and security. Similarly, we found substantial variation in "how" and "which" advice was provided – e.g. some records provided advice linked to specific age periods of the child while others provided general advice for children of any age.

Conclusion

A home-based record can be a useful tool to support and empower caregivers to take care of their family's health, including early childhood development. This review of a sample of home-based records from countries in different regions showed substantive variability in their comprehensiveness and content. This may well be due to the lack of a global standard, with multiple instruments in use globally. Milestones are commonly used to monitor children's development, but they vary in wording, multitude and time points. Relatively little attention is given to risk factors in the direct or family environment of the child. Hence, global guidance on minimum evidence-based content of home-based records for monitoring and parenting advice to support early childhood development will likely strengthen the potential of these records to improve child health and development outcomes.

ANNEX 3.

Summaries of presentations and panel discussions

Children with developmental delays, disorders and/or disabilities: building a continuum of care for early interventions.

Tarun Dua, WHO, and Hans Forsberg, UNICEF

The approach taken to building a continuum of care for early interventions is illustrated by two pyramids, one upside-down, depicting the depth/extent of services and the child's needs. The aim is to promote a child- and family-centred approach. Several major reviews have been carried out that contributed to this work. A search procedure was used to develop a target product profile for what is needed for developmental monitoring at the programmatic and at the population level. This work brought together some existing tools (the Caregiver-reported Early Development Instruments [CREDI], the Infant and Young Child Development [IYCD] package, and D-Score [a one-number summary that quantifies child development]) to develop the Global Scale of Early Development (GSED). The GSED benefits from various innovations, including its large database and its standardized approach for validation. There is a unique data bank including developmental monitoring information on more than 70 000 children involving 22 instruments. Validation of the GSED is ongoing in six countries across the diverse geography of the WHO Regions. A short- and a long-form GSED is being developed, as well as an app. The GSED produces a numerical value for tracking the child's development, i.e. the D-score, and uses pass/fail for the items in the tool. It allows quantitative comparisons within and between ages and countries, enables tracking of changes over time, and can allow for development of trajectories similar to those for height or weight. The testing is adapted to the age of the child. The team of UNICEF and WHO staff is also preparing the *Global report on developmental delays, disorders and disabilities* as well as programmatic guidance on strengthening approaches to developmental delay.

Other work is focusing on children with developmental delays and disabilities, using a rights-based approach. Particularly in low- and middle-income countries, the attention to these children is

not always evidence-based. These children and their families may suffer from stigma and discrimination, neglect, lack of or poor-quality services, and outdated methods. UNICEF is developing a systems model for early identification that is based on the principles of child rights, the International Classification of Functioning, and family-centred care, that is, community-based, multi-professional and evidence-based. UNICEF supports a "twin track approach". All children should be screened and monitored and receive anticipatory guidance as part of Tier 1. Children identified in need of additional services receive these as part of Tier 2. The team has produced and is supporting the use of screening tools and is working on advocacy. Ten manuscripts covering early developmental screening tools for certain conditions are under preparation.

Tier 1 includes screening for vision and hearing, crucial to be completed during the first months of life. Community-based interventions for children in Tier 2 include ones for visual and hearing impairment. New packages of interventions are being developed. The most specialized support is provided under Tier 3.

A review of available screening tools identified 140 unique ones. Ten of these screening tools meet all criteria for inclusion in further analysis. Three of them, the Guide for Monitoring Child Development (GMCD), mCHAT (for autism screening), and the Malawi Rapid Neurodevelopmental Assessment (0 - 2 years) can be recommended.

To test the approach for Tier 2, piloting is being conducted in three countries. Recommendations for the first two tiers have been completed with pathways for hearing, vision, cerebral palsy, and autism spectrum disorders. The second round focuses on testing the Tier 3 system in 2020.

Early detection and early intervention for children at risk of neglect or maltreatment

Alex Butchart and Berit Kieselbach, WHO

Child maltreatment may include physical, sexual, emotional or psychological abuse, or neglect. Figures show that child maltreatment is widespread, and that children who have suffered from maltreatment during childhood will likely have consequences, such as perpetuating violence, depression, obesity and substance abuse.

Front-line workers have an important role in early identification and first-line support for children at risk of or suffering neglect or maltreatment. Health providers, if trained, can provide support such as cognitive behavioural therapy. Pharmacological treatment is not recommended. Screening tools are

currently not very good and might imply dangers for false positives and false negatives. Rather than screening tools, it might be more important to emphasize the relation of the health worker with the family. It is crucial to link the health response with the law system and child protection.

WHO has produced guidelines on the health sector response to child maltreatment, including recommendations on, i.a. identification of child abuse and neglect, medical history taking, and mental health interventions. The team has developed a complementary handbook, and a handbook for health workers is under development.

Global recommendations and guidance to strengthen the role of home-based records

Annie Portela and Laura Nic Lochlainn, WHO, and Anne Detjen, UNICEF

There are many implementation considerations around home-based records. A wide variety of types exist, and they have grown in content over the years from simple Road-to-health cards to ones that include a variety of topics (antenatal, vaccine, maternal and child-focused). Many benefits of home-based records exist for both health care providers and service delivery, and for clients and caregivers. Traditionally, records were intended to be kept by the family at home, but they are also for health workers (potentially at different facilities) to ensure continuum of care. WHO produced recommendations on home-based records for maternal, newborn and child health in 2018. The process involved formulating questions and commissioning systematic reviews. While recommending home-based records, there was insufficient evidence available to determine if any specific type, format or design is more effective. Only 14 studies were found on the effectiveness of home-based records, and these were mainly in high-income countries. However, the records are valued by families and providers, and useful in weak and fragile settings.

Multi-sectoral records have different purposes, and the purposes may change over time. The more content there is, the more complex the records become, and the more difficult they are to use. They may also be costly to produce, and families may have to pay for them, creating an issue of equity for poorer families. This situation may change where electronic records are introduced.

Mapping of tools that support the implementation of home-based records is ongoing. Currently, 20 priority countries are involved to determine what they are tracking in the home and in facilities, and how these records relate to each other. The focus is on what should be priority information and advice for priority messages. One issue is whether the text in records corresponds to a population's literacy level.

UNICEF has a project with the Japanese International Cooperation Agency to advance this work at global level, focusing on monitoring data innovation, digital tools, and linking of records with patient messaging. Implementation guidance for programme managers is being developed.

Panel discussions

1. Viewpoints

a. Individual, family and community factors

- Which factors are important to consider when monitoring early childhood development?
- Which factors are feasible for use in developmental monitoring and counselling in primary care services?

b. Timing of monitoring early childhood development

- What are appropriate timings for monitoring children's development?

- What can be achieved in regular maternal, newborn and child health services?
- Is there justification for in-depth assessment of all children at specific moments in their life trajectory?

Ilgı Ertem considered that monitoring of child development should take place within a context of the family and community, within the bioecological theory. It needs to be based on the *Nurturing care framework*, and the International Classification of Functioning should also be considered. We need to consider what is functional and promotes children's participation in the community. We also need to monitor the strengths of the child, family and community.

Monitoring needs to be done in a partnering relationship between a family and a primary health care provider; the partnering relationship around the child's development is critical. Highly literate families may do this monitoring on their own. Screening only provides a pass/fail decision; monitoring shows where the child and family are. Monitoring has to incorporate what to do after the monitoring process has been completed, including possible referral. The person monitoring has to know how to support the family.

Monitoring should be done during the prenatal and neonatal period, and at six-month intervals for the first 3 years of life for a child with no risks and no delays. Otherwise, closer monitoring and support is needed. Immunization programmes can be strengthened with developmental monitoring, and there may be opportunities during home visits and in creches.

There is justification for all children to be monitored, but the feasibility of doing this in many services needs to be considered. Screening for autism should be done, but it needs to be built into an overall monitoring programme. The role of percentiles for monitoring children needs to be addressed.

Kate Milner noted that well-resourced systems are moving away from screening towards monitoring, and that the GMCD is very good for monitoring, but many tools are not. Feasible, appropriate and actionable domains should be monitored, but many existing tools are not always feasible and acceptable. What is asked of health care workers to measure (e.g. maternal well-being, adverse child events, violence) may be too much. There may be a need for sensitization of health workers, and they should be supported through training and supervision.

It is crucial for monitoring to be carried out in both the prenatal and neonatal periods. After that, the timing becomes context specific. A limitless number of items can be monitored. Special opportunities should be used, i.e. school entry.

Magdalena Janus remarked that screening is only as good as the referral and follow-up afterwards; if guidance for screening is provided, there also has to be guidance for follow-up. It is unethical to screen without follow-up. Development, especially in the first year of life, is very similar across countries, and the first years are where monitoring development is most useful. We need to compromise on what to monitor, given cultural and linguistic differences. There may be a need for a domain-based tool, such as the GSED.

Regarding timing and frequency, there is an issue of costs and benefits: what are the costs of *not* screening, as developmental monitoring and home-based records can make a difference in terms of money and investment, if care is provided early by preventing and reducing future costs of care. In Canada, only Ontario monitors universally at 18 months (other provinces have regional approaches). Even though there is only 60% uptake, it is done in well-baby visits. It is crucial to combine rigorous science with feasibility, and thus monitoring could be framed around such visits wherever they exist.

2. Experiences from the field

Opportunities across the continuum of care

- What are opportunities in maternal, newborn and child health (and other) services for monitoring early childhood development?
- What are facilitators and challenges?

Triggers for action

- What conditions should be met to ensure that monitoring leads to appropriate follow-up action?

Svetlana Drivdal noted that the first important aspect is normative. If there are early childhood development components, with milestones already in the guiding documentation in the system, then it is easier to implement them. If not, you have to start with integrating these aspects into routine systems, and experience shows that it is easier to add components. Training may be necessary. Nutrition work provides leverage for developmental monitoring, as they go well together. Preventive touchpoints are probably easiest, and after that malnutrition and HIV services. Follow-up actions are often a problem as there may be no next level to take referrals. Registers keep the information about the child at the primary health care level, but when a child is referred, he/she is seen as a new child without a history, and there is no continuity of care. There are many providers who could provide follow-up, but there may not be links between the different providers.

It is difficult to do developmental monitoring during a sick child visit, and preventive visits are a much better

opportunity, as are other routine monitoring contacts, e.g. if the child was premature, HIV-positive or has a chronic disease.

Aleksandra Jovic stated that the primary purpose of monitoring is to support the child and family and enable referral. Support must be strength-based. The system (health or other) needs to be considered, as it supports the front-line worker in how to approach and support parents. Countries need to know their pathways for families. Front-line workers are more familiar with a deficit-based and medical model to child development and developmental difficulties. Another major issue is lack of staff in many places. Early childhood development needs to be seen as a new area with specific terms of reference.

There is a need for guidance on standardized tools, and for shorter tools that can be used by front-line workers in the primary health care setting, as well as their training. More in-depth evaluations should be conducted when children are identified with additional needs. It is important to have transdisciplinary teams at the front-line level, and the change in approach needs to go into job descriptions. Progress can be made even with limited resources. UNICEF in the east and central Asia region is currently developing parenting apps in a number of countries that encourage the monitoring of the child with the caregiver, in response to a growing demand by parents. Countries need more evidence-based advocacy for developmental monitoring. Important issues exist with overcoming validation and standardization, as well as the licensing of instruments. Standards for indicators are needed.

Wiedaad Slemming stated that building competencies in caregivers and front-line workers is important. Focus on the family and the child from early on (before the clinical aspects). The referral path is critical but may be locally defined, allowing for local innovation. We have to increase caregiver demand, for example the South African national Side-by-Side campaign and Road-to-Health Book. Advocacy is ongoing and increasing demand will drive quality provision of more comprehensive child health services. In many countries screening is carried out, but then there is no conversation with caregivers about the screening. Peer-to-peer mentoring and good quality supervision is needed. Health worker counselling skills are lacking and need to be brought earlier into training, starting at the pre-service level, with reinforcement at in-service level. We should start focusing more on how to support families to provide responsive care and opportunities for learning, rather than focusing mainly on screening and milestone attainment, in health care interactions. It is difficult to talk about referral pathways, as often

no services are available. In such cases, we need to broaden the scope of health professionals who can provide further assessment and management for children and families who need it. Often this is determined by what services are available locally; thus we should support local innovations that aim to optimize service delivery for children with developmental difficulties and disabilities. Other examples of primary care approaches that can be used include peer educator programmes by nongovernmental organizations, and outreach from facilities to early childhood development centres. Better guidance on support for children's development, including assessment and follow-up, is needed.

3. Viewpoints

Opportunities for early intervention

- What is the potential for extra support to children identified to be at risk of with signs of developmental delay at primary care level?
- When is referral important and to whom?

Building capacity of the workforce

- Which cadres of health workers can be involved at different levels of the health system?
- What level of training and support do they need to perform their tasks appropriately?

Vibha Krishnamurthy noted that there needs to be a continuum of support to children at risk, a relationship of the provider with the family at the primary level (depending on the context, this could be a community health worker, nurse, paediatrician or other care provider). The first level of intervention should be the person having a relationship with the family.

Health workers may think that they are expected to cure children with developmental disabilities or delays, but they can only do their part on a continuum. Mistrust and stigma can be problems, as is referral when there are no specialists. Nongovernmental organizations may help.

It may not be easy for families to access resources, particularly how to navigate the system and move from Tier 1 to Tier 2 support.

It is important not to dilute responsive caregiving and early learning in integrated programmes on health and nutrition. There is concern that training will be insufficient, and that early childhood development might not have priority when it is added to growth and nutrition monitoring. Specific training of the health worker on early childhood development and responsive caregiving will also have to be done, including caring for children with special needs and severe problems.

Families are not used to family-centred and strength-based approaches, and providers are unlikely to have experienced responsive, strength-based approaches themselves. Families may need help to navigate the system.

Chiara Servili stressed the importance of maximizing their potential, minimizing barriers, and improving the environmental fit for children with developmental delays and disorders. Important elements to set targets for early interventions, and to develop management plans with families, are assessment of a child's development, functioning and health profiles; diagnostic assessment; understanding of family priorities; and community resources. This is a journey for children and families, not a one-time intervention. Setting treatment goals is complex as priorities in the child's or family's life change, as the child's development proceeds. Good assessment and consultation lead to a management plan.

A developmental and functioning profile is needed; having a diagnosis is not a requirement to access care and support, but may help define specific early intervention strategies. In fact, a diagnosis is often not available, or waiting for one may delay access to care and support. Also needed to start is information about family-level strengths, vulnerabilities and support, and community factors and barriers.

Countries that train non-specialist providers on the Mental Health Global Action Programme (mhGAP) mainstream developmental assessment and development of a management plan with the family within primary health care. The implementation of mhGAP requires countries to develop strategies to provide support for families and strengthen carers' skills.

The Caregiver Skills Training (CST) for families of children with developmental delays and disorders by WHO, developed to complement mhGAP, provides carers group-based and home-based opportunities for modelling and coaching on strategies to improve engagement of children in play and other everyday activities. It also aims to support children's development in communication and adaptive behaviours. The CST includes a component focusing on the caregivers' well-being and coping. It is implemented by a range of trained non-specialist facilitators (community-based providers, nurses, trained peer champions, etc.), in consultation and under the supervision of more experienced and specialized staff. Providers need to have the right set of competencies and to be family-centred. The CST is being implemented in more than 30 sites. Additional elements will be developed for lower-intensity work and responding to the diverse needs of families.

4. Reflections on the overall proceedings

- What did the evidence tell us?
- How can current practice be strengthened?
- What are gaps in knowledge that need to be filled?

Janna Patterson noted that we have many building blocks for early childhood development systems and a multiplicity of tools. However, some of the tools might not yet have the capacity to be integrated into health systems, and the terminology we use still lacks uniformity. To strengthen practices, we need to integrate and coordinate across sectors, including specialists and families. The primary level has to have a strong relationship with the family. Continuity of care over time is key to make interventions effective, including anticipatory guidance for caregivers of what to expect next in the child's development. There are many micro-moments/contacts that can be used to teach and model responsive caregiving. We need more implementation research on how to integrate these features more successfully.

Raoul Bermejo stressed that we have to look at early childhood development from a systems approach, i.e. the pathways of care, and build on universal approaches. The perspective of the child has to be taken into account when conceptualizing and providing global guidance for an early care system and the key components of a framework for this. Countries are at different stages: a framework with core elements should be provided to them. Tools are needed across the continuum of care for seamless pathways, and they need to take the child's ecosystem into account. Some lessons from this meeting should be taken on board by the *Global report on developmental delays, disorders and disabilities* being produced by UNICEF and WHO. Stigma and discrimination need to be addressed, and access to services improved further.

Mark Tomlinson emphasized that families and caregivers need to become true partners of providers, and that we need to focus on relationships over tools. Babies and children only exist in relationships, and hence we should always look at relationships between the child, caregiver and family. It is a life course pathway. Children do not develop across datapoints but over time and in partnership. We have to be careful that screening results are interpreted carefully. Implementation research should be conducted to see how home-based records can be used better for relationship-building between providers and caregivers.

ANNEX 4.

Proposed agenda

Monitoring of children's development by primary care workers

9 – 10 June 2020, 13.30 – 17.00 hours (Geneva time)

Chairpersons: Linda Richter, Mark Tomlinson
 Rapporteurs: Peggy Henderson, Kid Kohl, Bettina Schwethelm
 The sessions will be recorded

Tuesday 9 June

Chairperson: Linda Richter		
13.30 – 14.00	Welcome Introduction of participants Declarations of interest	Anshu Banerjee
14.00 – 14.05	Working procedures	Bernadette Daelmans
14.05 – 14.30	A continuum of care for monitoring early childhood development: what are the issues? Questions and answers	Linda Richter
14.30 – 15.00	Literature review: Terminology, evidence highlights Clarifications	Xanthe Hunt
15.00 – 15.30	Home-based records and counselling cards: Overview and highlights Clarifications	Kid Kohl
15.30 – 15.40	Break	
15.40 – 16.15	Viewpoints <i>Individual, family and community factors</i> – Which factors are important to consider when monitoring early childhood development? – Which factors are feasible for use in developmental monitoring and counselling in primary care services? <i>Timing of monitoring early childhood development</i> – What are appropriate timings for monitoring children's development? – What can be achieved in regular MNCH services? – Is there justification for developmental assessment of all children at specific moments in their life trajectory?	<i>Discussants</i> 5 minutes each – Ilgi Ertem – Kate Milner – Magdalena Janus Questions and observations from participants
16.15 – 16.45	Experiences from the field <i>Opportunities across the continuum of care</i> – What are opportunities in maternal, newborn and child health (and other) services for monitoring early childhood development? – What are facilitators and challenges? <i>Triggers for action</i> – What conditions should be met to ensure that monitoring leads to appropriate follow-up action?	<i>Discussants</i> 5 minutes each – Svetlana Drivdal – Aleksandra Jovic – Wiedaad Slemming Questions and observations from participants
16.45 – 16.55	Preliminary conclusions	Linda Richter
16.55 – 17.00	Closing for the day	Bernadette Daelmans

Wednesday 10 June

Chairperson: Mark Tomlinson		
13.30 – 13.35	Welcome and agenda for the day	Bernadette Daelmans
13.35 – 14.10	Children with developmental delays, disorders and/or disabilities: building a continuum of care for early interventions.	Hans Forsberg Tarun Dua
	Clarifications	
14.10 – 14.30	Early detection and early intervention for children at risk of neglect or maltreatment	Alex Butchart
	Clarifications	
14.30 – 15.00	View points	<i>Discussants 5 minutes each</i>
	<i>Opportunities for early intervention</i>	– Vibha Krishnamurthy – Chiara Servili
	– What is the potential for extra support to children identified to be at risk of or with signs of developmental delay at primary care level?	
	– When is referral important and to whom?	Questions and observations from participants
	<i>Building capacity of the workforce</i>	
	– Which cadres of health workers can be involved at different levels of the health system?	
	– What level of training and support do they need to perform their tasks appropriately?	
15.00 – 15.30	Global recommendation and guidance to strengthen the role of home-based records	Anne Detjen Annie Portela
15.30 – 15.40	Break	
Chairperson: Linda Richter		
15.40 – 16.00	Reflections on the overall proceedings	<i>Discussants 5 minutes each</i>
	– What did the evidence tell us?	– Raoul Bermejo
	– How can current practice be strengthened?	– Janna Patterson
	– What are gaps in knowledge that need to be filled?	– Mark Tomlinson
16.00 – 16.45	Review of meeting conclusions	Linda Richter
16.45 – 17.00	Next steps and closing	Bernadette Daelmans

ANNEX 5.

Glossary of terms⁴

Anticipatory guidance - is defined as proactive counselling that addresses the significant physical, emotional, psychological and developmental changes that will occur in children and can be oriented around touch points (or predictable developmental spurts).

Childhood disabilities – these refer to any difficulties experienced in any three areas of functioning – impairment, activity limitation and restricted participation – as a result of a health condition and the interaction of this with the environment. It includes chronic health conditions such as asthma, diabetes, epilepsy and obesity.

Developmental difficulty – any condition that puts a child at risk of sub-optimal development, or that causes a child to have a developmental deviance, delay, disorder or disability. The term encompasses all children who have limitations in functioning and developing to their full potential. This includes those living in hunger or social deprivation, those who had a low birth weight, and those with cerebral palsy, autism, sensory problems, cognitive impairments (such as Down syndrome), or other physical disabilities, such as spina bifida.

Developmental disabilities – a group of conditions due to an impairment in physical, learning, language or behaviour areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime, e.g. hearing, vision impairments, cerebral palsy.

Neurodevelopmental disorders – a group of behavioural and cognitive disorders arising during the developmental period that involve significant difficulties in the acquisition and execution of specific intellectual, motor or social functions.

Transdisciplinary care – is a model where one clinician, who can be a primary health care provider, takes on primary responsibility for the child and family. This clinician can then seek information about specific aspects of the child's or family's difficulties by consulting written materials or experts in related disciplines and thus work across disciplines to provide care. In early intervention, transdisciplinary, non-fragmented care is regarded as the gold standard. This approach also avoids confusion of families and promotes cost-effective use of resources.

4. Adapted from WHO publications, except for transdisciplinary care (Igli Ertem, personal communication, 2020).



Department of Maternal, Newborn, Child and Adolescent Health and Ageing
World Health Organization

https://www.who.int/maternal_child_adolescent/en/

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