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MONITORING CHILDREN'S DEVELOPMENT THROUGH PRIMARY HEALTH CARE IN EUROPE AND CENTRAL ASIA

Directions for policy and practice



ABSTRACT

This publication was developed by the United Nations Children’s Fund (UNICEF) Regional Office for Europe and Central Asia and the World Health Organization (WHO) Regional Office for Europe, with Dr. Revan Mustafa as the key author. It aims to support policy makers, professionals, advocates and academics in introducing developmental monitoring as a part of routine child health services at the primary health care level.

The publication provides guidance for professionals on the essentials of developmental monitoring and how to apply it in practice. It also presents a set of recommended actions on how to strengthen the health system elements necessary for the effective implementation of developmental monitoring, based on the available literature and findings regarding the current status of developmental monitoring in the region.

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ABBREVIATIONS

CDA | Comprehensive Developmental Assessment

ECAR | Europe and Central Asia region

ECARO UNICEF | Regional Office for Europe and Central Asia UNICEF

ECD | Early Childhood Development

ECI | Early Childhood Intervention

ICF | International Classification of Functioning, Disability and Health

M&E | Monitoring and Evaluation

NCF | Nurturing Care Framework

PHC | Primary Health Care

UNICEF | United Nations International Children's Emergency Fund

WHO | World Health Organization

TERMS AND DEFINITIONS

Allied health professionals are professionals from different disciplines, such as psychology, midwifery and special education, who may be employed in health systems to conduct developmental monitoring.

Comprehensive developmental assessment is a detailed assessment conducted to establish a specific diagnosis, assess the child's developmental functioning, identify the needs of the child and family for additional support and services, and to link the child and the family to such services.

Child health supervision protocol. This term refers to an official document issued by a ministry of health or authorized professional organization and defines the activities, examinations and procedures that are regarded as mandatory as a part of the provision of the primary health care services for children. It will be used synonymously with the following terms: National protocol, practice guidelines, well-child visits, national programme of health care of newborns, children and adolescents.

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

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 any aberrations. Developmental monitoring enables the child's functioning to be interpreted by looking at factors such as expressive communication, receptive communication, gross motor and fine motor skills, relating, play and self-help. It supports how the family provides stimulating, nurturing care in the child's daily life. It looks for biopsychosocial risk factors that may be present and assesses how the family is dealing with these risk factors. It educates providers about the rights of children with developmental difficulties, and provides information on how to support families using interventions, including community-based resources.

Developmental risk is a factor that may impede child development and result in a suboptimal developmental trajectory.

Early childhood development encompasses a critical period of child development from birth to the preschool years – when genetic endowment and the environment interact to shape the brain's wiring for the acquisition of cognitive, language and socioemotional skills – and other higher brain functions.

Early intervention means identifying and providing effective early developmental support to children and young people who are at risk of poor outcomes.

Family will be used throughout the document to stand for adults or children who are taking care of a child. 'Family' may stand for a paid or unpaid caregiver, biological or adoptive parents, grandparents, siblings and other members of the extended family. The term 'parent' will also be used when necessary, specifically to indicate a mother or father or other caregivers.

Health care provider refers to a trained professional involved in the provision of health care services (doctors, nurses or allied health professionals).

Neonatal screening is the administration of a simple test (either in the laboratory or during a clinical examination) during the newborn period, with the aim of identifying frequently occurring medical conditions (that may not be clinically evident in the neonatal period and, if left untreated, may have a high public health impact), for which there exists an effective treatment as long as the condition is identified sufficiently early.

Programme will be used in this document to refer to systematic measures to implement a service or a practice, for example an immunization programme. Programmatic will refer to the aspects of the programme.

Survey refers to the web-based survey described in Chapter Two, Methods, conducted with UNICEF health and ECD officers, unless otherwise specified.

Standardized developmental monitoring tool refers to a standardized and validated tool for the assessment of child development across several developmental domains within the context of the child's family and community. It determines strengths, protective factors and potential risks, and leads seamlessly into providing the support and interventions that a child needs. This term is not to be used synonymously with 'screening tool'.

Standardized developmental screening tool refer to a standardized and validated tool (either a questionnaire or checklist) which tests the child by asking questions about development, including language, movement, cognitive abilities, behaviour and emotions. Screening tools aim to identify children who have developmental skills below those expected for their age.

EXECUTIVE SUMMARY

This publication aims to provide an overview of the state of developmental monitoring in selected countries across the Europe and Central Asia region (ECAR), to document the existing evidence-based approaches and models for developmental monitoring and to identify the key considerations necessary to guide discussions around introducing and enhancing developmental monitoring as a part of primary health care.

After setting out the standards of care and assessing the current state of developmental monitoring, the publication outlines the key recommended actions for the region's health systems. The publication also provides documented examples of good practice across the region on different aspects of developmental monitoring. The findings do not claim to be representative, but rather illustrative of the different practices along the spectrum of implementation in the region.

The standards of care for developmental monitoring were compiled from seminal publications on developmental monitoring by the World Health Organization (WHO), the United Nations International Children's Emergency Fund (UNICEF) and leading authors in the field. The information on the current state of implementation of developmental monitoring – in terms of the core components existing within health systems in Europe and Central Asia– was compiled and contextualized based on:

- **A web-based survey of UNICEF health officers from the region**
- **A focused search and review of published literature**



THE IMPORTANCE OF EARLY CHILDHOOD DEVELOPMENT AND DEVELOPMENTAL MONITORING

Early childhood is the period that lays the foundations for health, well-being, learning, and productivity throughout the course of a person's life. It also has an impact on subsequent generations. Conditions that ultimately result in deficiencies in a person's health, inadequate nutrition, a lack of safety and security, unresponsive caregiving or limited opportunities for early learning may adversely affect a child's health and development and prevent children from fulfilling their developmental potential. This wide array of conditions that put a child at risk of suboptimal development, or cause a child to have a developmental deviance, delay, disorder or disability are defined as 'developmental difficulties'. Although the true global prevalence of developmental difficulties remains unknown, estimates based on proxy measures of stunting and poverty point to a very high prevalence (43%) in low- and middle-income countries. A systematic, holistic and comprehensive approach embedded in scientific evidence must therefore be pursued to promote early childhood development and address developmental difficulties.

WHAT IS DEVELOPMENTAL MONITORING?

Developmental monitoring is an approach that aims to keep track of, and support, every child's development. In developmental monitoring health care providers:



Inform families about the importance of early brain development.



Look for biopsychosocial risks possibly impeding development and assess how the family is dealing with them. Partner with families to enhance strengths, address risk factors, and provide additional individualized support and services when needed.



Ask about any concerns regarding their child's development.



Interpret child's functioning by assessing expressive communication, receptive communication, gross motor and fine motor skills, relating, play and self-help.



Partner with families to enhance strengths, address risk factors, and provide additional individualized support and services when needed.



Learn about the nurturing environment of the child and the family's efforts to help the child develop with aim of supporting the family.

Early childhood is the period that lays the foundations for health, well-being, learning, and productivity throughout the course of a person's life.

The evaluation of health systems in relation to state of implementation of developmental monitoring within primary health care was conducted using the WHO health system building blocks framework.

Standardized, validated, culturally appropriate and theory-based tools are used in the context of developmental monitoring to enable health care providers understand how the child is developing across the domains of development, identify developmental delays, recognize the need for extra support, and provide individualized instructions on how to support the next steps in the child's development. Individualized support for the child's development is then provided by the parents through the daily activities that children and families typically engage in. These activities focus on promoting functional skills, prioritize routines such as play, home chores, spending time in nature, and engagement in relationships within an extended family and community context. Health care providers may also offer guidance on how to access services that will support the child and the family.

Health care providers do not use these tools with the aim of 'screening for delays', nor with the intention of segregating children into those who are delayed vs. those who are not. This is because the ultimate aim of developmental monitoring is not confined to just finding children with suboptimal development and referring them to the relevant services, but instead, to start providing individualized developmental support for every child right there and then.

It is best when developmental monitoring is provided by the professional whom the family knows well, and has regular contacts with. In many health systems, this is typically a family physician, a nurse, or a midwife. However, this could be any allied health professional, or even a community health worker. All care providers involved in developmental monitoring should be trained in the theory, skills and attitudes required to conduct developmental monitoring. It is important that a physician is available to help address health-related risks that that might be present, or provide guidance and supervision on some specific situations.

The ultimate aim of developmental monitoring is not confined to just finding children with suboptimal development and referring them to the relevant services, but instead, to start providing individualized developmental support for every child right there and then.

CURRENT STATE OF DEVELOPMENTAL MONITORING IMPLEMENTATION AND MAJOR RECOMMENDED ACTIONS FOR HEALTH CARE SYSTEMS IN EUROPE AND CENTRAL ASIA

Countries in the Europe and Central Asia region are increasingly recognizing the importance of addressing developmental difficulties within routine health care service provision. As a result, countries have already started shifting routine health care service delivery from 'medical care only' to a comprehensive provision focusing on child development.

Health care providers do not have sufficient time or adequate training, and they do not use validated tools to conduct developmental monitoring.

There is clear evidence of this happening across the region – countries are adopting new legislative acts, conducting situational analyses and exchanging experience to come up with some truly innovative solutions to introduce developmental monitoring. Support from international organizations, such as UNICEF and WHO, has been instrumental in the success of these efforts.

The regional health systems' shared features enable generalisations about their potential for furthering the introduction of developmental monitoring. Most of the time, countries in the region possess a well-developed primary health care infrastructure, the population's access to basic primary health care services is high, the main professionals providing services (i.e., physicians or nurses) are trusted in their communities, and many countries have a home-visiting system in place.

Yet the primary challenges preventing the universal introduction of developmental monitoring in the region were articulated more than a decade ago, and remain unchanged: Health care providers do not have sufficient time or adequate training, and they do not use validated tools to conduct developmental monitoring. Ultimately, the root causes of these barriers need to be addressed in order to make developmental monitoring a standard of care within routine service provision.

The notion that physical health and development are two inseparable halves of a holistic concept of 'health' has been very slow to translate into practice. Also, the training of health care providers does not align with the holistic conceptualization. As a result, the training of primary health care providers has traditionally focused on medical issues, while everything related to child development was considered to belong to 'other' specialists working in higher levels of health care or rehabilitation facilities. Where available, the training curricula of primary health care providers are still mostly confined to merely teaching milestones, red

flags, screening tools or checklists. Such a narrow set of detached skills does not equip primary health care providers with the clinical competencies they require to provide developmental monitoring. **Training curricula need to deliver clinical competencies related to child development in the same way they have achieved this for other priorities, such as antenatal care.** The training curricula of all professionals involved in developmental monitoring should align with bioecological theory, nurturing care and family-centred, strengths-based care, as well as World Health Organization International Classification of Functioning, Disability and Health.

Health care providers frequently do not use standardized and validated tools for developmental monitoring, yet they cannot rely on their clinical experience alone to identify developmental difficulties; they will inevitably fail to identify most of the children in need of support. **Health care systems need to provide and allocate resources for procuring brief, user-friendly, standardized and validated tools for developmental monitoring and provide training to facilitate their use.**

The role of primary health care providers in addressing child development has been traditionally reduced to 'screening' and referral. Identification based on clinical experience alone, 'screening and referral,' or self-referral upon parental concern do not automatically translate into proper support for young children and their families. Even when there are excellent early intervention services available, few children with developmental difficulties and their families can benefit from them if systematic developmental monitoring is not conducted at the primary health care level. If systematic developmental monitoring is not conducted at the primary health care level, many children with developmental difficulties are likely to go unnoticed or unsupported.

Our knowledge about early childhood development and the huge burden of developmental difficulties calls for a prioritization of universal developmental monitoring during the routine contacts that young children have with health care. Universal means that all children and families receive individualized support for their development. Children with developmental difficulties and their families should receive more support. **Health care systems need to introduce policies that mandate universal developmental monitoring while providing the relevant training and allocating sufficient resources (such as staff time and incentives) to put these policies into practice.**

In some countries, children may also not receive developmental monitoring if their families need to make an out-of-pocket payment for this service. In other instances, even if the child is eligible for free-of-charge developmental monitoring, it still may not be delivered because there are no incentives for service providers to deliver it (or penalties if they don't). **Governments need to include developmental**

If systematic developmental monitoring is not conducted at the primary health care level, many children with developmental difficulties are likely to go unnoticed or unsupported.

A lack of understanding about the importance of early childhood development at the policy maker level has shown to translate into little or no progress for some countries.

monitoring as an integral component of routine child health care, securing the necessary financial resources in order to mandate and incentivize its implementation. In performance-based health care, a more balanced incentivization scheme should be implemented.

Nowadays, many regional health systems have transitioned from paper based data collection to electronic data collection using Health Management Information Systems which is very important to support planning, analysis, management and decision making in healthcare. **Data on developmental monitoring derived from health care provider-patient interactions should also be included in Health Management Information Systems and linked with other data, such as immunization.** However, this is yet to happen in many countries across the region.

Health care systems also need to consider developmental monitoring as a service in need of its own monitoring and evaluation, and collect feedback on how this service is being implemented. Such feedback is a powerful input for the service design and planning. A participatory approach to monitoring and evaluating developmental monitoring means that everyone's opinions about what to monitor and evaluate are taken into account, including families as end beneficiaries. Such approaches are highly effective for the sustainability of this resource-intensive activity.

A lack of understanding about the importance of early childhood development at the policy maker level has shown to translate into little or no progress for some countries. Others have succeeded in taking contingent steps towards creating the necessary conditions and resources for the dissemination and implementation of developmental monitoring. Some of these countries have even established inter-ministerial working groups or similar bodies for early childhood development. **Thus, it is very important to secure consensus among the key stakeholders (academics, advocates, clinicians and policy makers) on the key priorities, as well as securing each government's commitment to prioritizing and securing resources for developmental monitoring.**

Shared understanding about the importance of early childhood development should translate into health care policy. **Governments must issue regulations, agreements, standards of care and practice guidelines regarding early childhood development, developmental monitoring and developmental difficulties.** These are important preconditions to releasing the necessary resources (financial, human, incentives and mandates) for developmental monitoring.



WHAT NEEDS TO HAPPEN?

1. Include universal developmental monitoring as an integral component of routine child health care and secure the necessary resources (financial, human resources, mandates, incentives) to facilitate its implementation.
2. Identify opportunities to introduce training in developmental monitoring within the existing curricula or take advantage of brief in-service trainings. Allocate sufficient resources (release trainees from duties, secure administrative and logistical support) for the trainings.
3. Make sure the training curricula deliver clinical competencies related to child development and are aligned with bioecological theory, nurturing care and family-centred, strengths-based care, as well as World Health Organization International Classification of Functioning, Disability and Health.
4. Allocate resources for procuring brief, user-friendly, standardized and validated tools for developmental monitoring. Follow best practices for adaptation. Secure resources for adaptation and training.
5. Define developmental monitoring as an essential health service that needs to be delivered as part of primary health care package; assign a distinct code for reimbursement where applicable. In performance-based health care, implement a balanced incentivization scheme that avoids under prioritization of developmental monitoring.
6. Facilitate collection of data on the results and outcomes of developmental monitoring via Health Management Information Systems. Consider developmental monitoring as a service in need of its own monitoring and evaluation, gather feedback on its implementation. Analyse and utilize collected data for planning and decision-making.
7. Accelerate discussions within and between ministries on intra- and inter-sectoral coordination and collaboration on promoting early childhood development, early identification of young children with developmental difficulties, and early intervention.
8. Work towards developing National Early Childhood Strategy, relevant regulations, child health supervision protocols and practice guidelines that reflect the contemporary conceptualization of early childhood development.



CHAPTER 1

Introduction and
conceptualization
of developmental
monitoring



A large amount of scientific knowledge has accumulated on the importance of early childhood development (ECD) for societal prosperity. Early childhood is the period that sets the foundations for health, well-being, learning, and productivity over the course of a person's life, and has an impact on subsequent generations.(1, 2)

Awareness of the importance of ECD is reflected in the United Nations Sustainable Development Goals (3). The World Health Organization (WHO) and the United Nations International Children's Emergency Fund (UNICEF) have also launched the Nurturing Care Framework (NCF), which clarifies that ECD efforts need to be theory- and framework-based and holistic. (4)

The NCF indicates that good health, adequate nutrition, safety and security, responsive caregiving and opportunities for early learning are all central to the development of children. This framework aims to provide governments and societies with strategic directions for the holistic support of children's well-being and has inspired multiple sectors, including health, education, labour, finance and social and child protection, to consider what they can do to promote the development of children.

Despite the long-established importance of ECD, the translation of theory into practice is still slow and uneven.(1) The Lancet ECD series points to an unacceptably high number of children who are unable to fulfil their developmental potential, with a large number living in low- and middle-income countries.(1) Being unable to fulfil one's developmental potential stands for a suboptimal developmental trajectory, decreased school readiness and learning abilities, and ultimately, decreased adult productivity. Any condition that puts a child at risk of suboptimal development, or that causes a child to have a developmental deviance, delay, disorder or disability is defined as a developmental difficulty. (4) A wide array of conditions resulting in deficiencies in one or more components of the NCF may adversely affect a child's well-being during this period and result in developmental difficulties.

The true global prevalence of developmental difficulties is unknown; however, it is estimated to be high, given its broad definition. Surveys of developmental disability provide us with an estimate that one out of every six, or 17%, of children in the United States have a developmental disability.(5) Estimates of the prevalence of developmental difficulties based on proxy measures of stunting and poverty point to a prevalence of 43% in low- and middle-income countries.(1)



1 out of 6

or 17%, of children in United States have a developmental disability. However, the prevalence of developmental difficulties is much higher.

WHAT CAUSES DEVELOPMENTAL DIFFICULTIES?

The causes of developmental difficulties in early childhood can be health-related or psychosocial.(6) From the most to the least common, the causes are:



1. **Inadequate nurturing, responsive care and early learning opportunities.** These may be due to a lack of knowledge about how to support development during infancy and early childhood, or the family's inability to support their child's development due to stressors such as poverty, physical or mental health problems among family members, natural disasters, or humanitarian crises



2. **Undernutrition**



3. **Micronutrient deficiencies,** such as iron and iodine deficiency



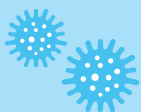
4. **Perinatal problems,** such as prematurity, asphyxia and intrauterine growth restriction



5. **Chronic illness,** such as congenital heart disease or cystic fibrosis



6. **Accidents and trauma**



7. **Infections that lead to impairments or undernutrition,** such as human immunodeficiency virus infection, meningitis, otitis, malaria and giardiasis



8. **Congenital/genetic/metabolic/inborn developmental disorders,** such as autism spectrum disorder, Down syndrome or hypothyroidism



9. **Hearing or visual impairments**



10. **Exposure to toxic substances** either in utero (e.g., alcohol) or postnatally (e.g., lead), either alone or in combination.

Public health measures in most countries have programmes for the primary, secondary and tertiary prevention of the causes of developmental difficulties. A detailed discussion of these prevention measures is beyond the scope of this publication; however, interested readers are referred to an exemplary model for the prevention of developmental difficulties provided in Annex 2, which is an excellent resource that may help advocates, clinicians, researchers and policy makers to think holistically about the programmatic aspects of prevention.(6)

Irrespective of their causes, developmental difficulties in early childhood often manifest with delays in language, relating, play, motor function or self-help skills. A systematic, holistic and comprehensive approach embedded in the bioecological theory of early childhood development must be pursued to prevent, identify and address developmental difficulties as early as possible.(6)

Developmental monitoring represents such an approach, and means to keep track of, and support, every child's development. This approach aims to maximize every child's developmental potential through ECD promotion, early identification of developmental difficulties and the provision of timely early intervention.(7, 8) The text below outlines the tenets of developmental monitoring based on seminal publications published in the last two decades.(4, 7-11)

CONCEPTUALIZATION OF DEVELOPMENTAL MONITORING

Developmental monitoring uses a holistic and comprehensive approach to promote ECD, identify developmental difficulties early, and provide early intervention. In this approach, health care providers build a relationship with the family and apply principles of family-centred care. They inform families about the importance of early brain development, ask about any concerns the parents or family members may have regarding their child's development, learn about the child's nurturing environment and about what the family is doing to provide support and inquire about any risks impeding development, the resources at the family's disposal, and their strengths and coping strategies. They also learn about the specific strengths of the children and families, empower them by acknowledging these strengths, and provide them with guidance on how to access services that will support them.

Health care providers use standardized and validated tools that are culturally and clinically appropriate and theory-based to monitor development, identify delays and assess the need for extra support.

Health care providers build a relationship with the family and apply principles of family-centred care.

Health care providers use standardized and validated tools that are culturally and clinically appropriate and theory-based to monitor development, identify delays and assess the need for extra support.

Health care providers do not use tools to 'screen' for delays and then segregate children into those who are delayed vs. those who are not delayed. This is an important point because developmental monitoring is not limited to finding children with suboptimal development and referring them for services. Health care providers use these tools to understand how the child is developing in the domains of language, play, relating and motor skills, identify developmental delays, recognize the need for extra support, and provide individualized support for the next steps in the child's development.

Individualized support for the child's development is then provided by the parents through the daily activities that children and families typically engage in. These activities focus on promoting functional skills, prioritize routines such as play, home chores, spending time in nature, and engagement in relationships within an extended family and community context. Health care providers also provide families with guidance on how to access services that will support them. Children and families who require extra support are referred to appropriate, accessible, evidence-based services in the community. Such transitions are seamless and avoid disruptions in the continuity of care.

Developmental monitoring is best provided by the professional with the best knowledge of and closest contact with the family. In typical healthcare settings, this could be a family physician, a nurse, or a midwife. However, any allied health professional, or even a community health worker can deliver developmental monitoring. It is important that this professional possesses a set of core clinical competencies to provide developmental monitoring. It is important that a physician is available to help address health-related risks that that might be present, or provide guidance and supervision on some specific situations. All professionals involved in developmental monitoring are trained according to the same theory- and evidence-based conceptual framework, which includes bioecological theory, nurturing care and family-centred, strengths-based care.

DEVELOPMENTAL MONITORING AND HEALTH CARE SYSTEMS

As understanding of the importance of supporting ECD becomes more widespread, many countries have pursued different approaches to putting this knowledge into practice and implementing the necessary services in real-world situations. Many European Member States have succeeded in introducing a developmental focus within routine health care provision.(12) However, a sustained focus on ECD is essential to continue prioritizing this important agenda, as **a majority of European Member States did not enlist** late identification of developmental difficulties as a top priority for their child and adolescent health strategy.(13)

Supporting ECD and conducting developmental monitoring is a complex task which falls under the remit of multiple sectors, such as health, education and social protection. However, the health sector's role stands out most prominently for several reasons.(6) Firstly, health systems already have the necessary infrastructure to reach all young children and their families. Secondly, health systems already cover aspects of physical health that are integral to children's well-being and development. Thirdly, families of children generally have trust in – and frequently contact – their health systems for antenatal care, growth monitoring, immunizations and in cases of illness. Contact with the health system is more frequent when children are young, and it provides a unique opportunity to address all the NCF components that have an impact on children's well-being and development. Last but not least, health systems can potentially provide links to other related sectors, such as social protection, that deal with aspects integral to supporting a child's broader well-being.

The growing interest in applying a developmental focus to health care service delivery and integrating ECD across health, education, and social protection systems has become increasingly prominent among countries in Europe and Central Asia over the past few decades. Despite the consensus that developmental monitoring needs to be implemented in order to prevent and address developmental difficulties, there is a lack of uniform understanding of what developmental monitoring is – and how it can be implemented.(9)

This demand for developmental monitoring to become an integral part of health care provision has led the WHO Regional Office for Europe and the UNICEF Regional Office for Europe and Central Asia (ECARO) to provide technical assistance and guidance.

A majority of European Member States did not enlist late identification of developmental difficulties as a top priority for their child and adolescent health strategy.

THE SCOPE OF THIS PUBLICATION

This publication aims to outline the optimum standards for developmental monitoring, map current developmental monitoring practices in selected European and Central Asian countries and identify positive examples, while drawing attention to any factors that may hinder the successful implementation of developmental monitoring.

In particular, this work researches and documents existing evidence-based approaches and models for developmental monitoring across Europe and Central Asia, and identifies key considerations that may guide discussions around introducing developmental monitoring as part of primary health care systems worldwide. The document is intended for use by academics, advocates, clinicians and policy makers who want to accelerate the introduction of universal developmental monitoring in their countries.

This work researches and documents existing evidence-based approaches and models for developmental monitoring across Europe and Central Asia.

The scope of this document encompasses developmental monitoring activities provided at the primary health care level from birth to the start of primary education, including the prevention of risk factors relevant to this age bracket and the relevant aspects of the early intervention system.

This document does not specifically focus on developmental monitoring conducted by trained professionals at higher levels or outside of the health system. Nor does this document focus on health promotion and risk-prevention activities, which are integral to the overall well-being of children as part of the lifecycle approach but which are extensively covered in other relevant documents, including: antenatal care, breastfeeding, growth monitoring, neonatal screening, obesity screening and management, hypertension screening in children, prevention of adolescent pregnancy, etc. Similarly, this publication does not focus on early intervention services for children with an already-identified developmental delay/disability or with known developmental risks or school-aged children.

Chapter Two will outline this publication's methodology and list sources of information used to assess how aspects of developmental monitoring are being implemented in the region. A brief outline of the World Health Organization Health System Building Blocks framework, which was used to guide the assessment, structure and presentation of the findings together with key recommended actions, will also be provided within this section.

Chapter Three forms the main text of this publication. This section examines and explains the optimal standards for developmental monitoring, outlines their current state of implementation, and shares the key considerations for furthering their implementation in the future.

The text in this section follows the structure set out by the World Health Organization Health System Building Blocks.

The publication is also supplemented by case studies from all over the world, highlighting examples of good practice which are relevant to implementation of developmental monitoring. Interested readers can refer to the references and annexes sections for more details.



CHAPTER 2

Methods



This document looks at the standards of care and examines the current state of implementation of developmental monitoring in selected countries in Europe and Central Asia before outlining key recommended actions for health systems worldwide. The publication also provides documented examples of good practices with regard to different aspects of developmental monitoring.

The publication's findings do not claim to be representative but rather illustrative of the many different practices being implemented in the region.

2.1 | STANDARDS OF CARE

The optimal standards of care related to developmental monitoring that this publication presents were compiled based on landmark publications published by WHO, UNICEF and leading authors. (6, 7, 9-11)

2.2 | SOURCES FOR ASSESSING THE CURRENT STATE OF IMPLEMENTATION

Information detailing the current state of implementation of development monitoring and its core components in European and Central Asian countries' health systems has been compiled from:

1. A web-based survey of UNICEF health officers from selected European and Central Asian countries. These UNICEF health officers were invited to participate based on their responses within internal UNICEF reporting streams, revealing that their countries have made progress in universalizing developmental monitoring. The health officers (from Armenia, Belarus, Bosnia and Herzegovina, Croatia, Moldova, Northern Macedonia, Serbia and Türkiye) were asked to reply to a survey questionnaire that assessed different aspects of developmental monitoring in their country. When providing responses to the survey, they consulted with national experts and partners.

The survey was prepared by a hired consultant, Snežana Ilić, in consultation with UNICEF and WHO technical staff. The WHO Health System Building Blocks framework was used to structure the survey. A sample survey form used for collecting information is provided in Annex 1. Structured, in-depth interviews were also conducted with UNICEF health officers from Armenia, Belarus and Serbia to learn additional details about the status of developmental monitoring in their respective countries.

2. A focused search and review of published literature (including research articles, books, situational analyses, reports and grey literature).

2.3 | ANALYTICAL FRAMEWORK USED TO ASSESS HEALTH SYSTEMS

This assessment of the current state of developmental monitoring and its implementation across Europe and Central Asia was organized according to the WHO Health System Building Blocks. This analytical framework was developed by WHO to ensure clarity of communication about the challenges, needs and actions necessary to strengthen health systems.⁽¹⁴⁾ The framework describes six distinct, although interrelated, elements that make up a health system and define its functions.⁽¹⁴⁾

In the next section, each aspect of the developmental monitoring process will be categorized according to the WHO building block to which it corresponds best. This pragmatic approach aims for comprehensibility, although the interrelated nature of the building blocks should be acknowledged.

THE WHO HEALTH SYSTEM BUILDING BLOCKS FRAMEWORK

LEADERSHIP AND GOVERNANCE

As a health system's most critical building block, this refers to the role of government in overseeing and guiding the whole health system while protecting the public interest.

FINANCING

This building block is concerned with raising enough funds to ensure the provision of health care services for the population.

INFORMATION

A well-functioning health information system ensures the production, analysis, dissemination and use of reliable and timely health information by decision makers. This means the development of health information and surveillance systems, the development of data-gathering tools and the collation and publication of international health statistics.

MEDICAL PRODUCTS, VACCINES AND TECHNOLOGY

Health care systems require established norms, standards and policy options regarding the procurement of equitable access to quality, safe medical products, vaccines, and technology, alongside the development, testing and use of new products.

HEALTH WORKFORCE

Comprising those whose work primarily focuses on protecting and improving health, a country's health workforce consists broadly of health service providers and health management and support workers. A 'well-performing' health workforce is available, competent, responsive and productive.

SERVICE DELIVERY

Looking at how inputs and services are organized and managed to ensure consistent access to quality, safe health care regardless of health conditions, location or time. This is about delivering effective, safe, quality services to the population in an efficient manner. Good service delivery requires appropriately trained staff with access to the necessary equipment and adequate financial support. It also requires a stable organizational environment which provides appropriate incentives to providers and users.



CHAPTER 3

Developmental
monitoring in selected
countries in Europe
and Central Asia and
recommended actions
to health systems



3.1 SERVICE DELIVERY

3.1.1. | ESSENTIAL ELEMENTS OF DEVELOPMENTAL MONITORING

A. APPLYING PRINCIPLES OF FAMILY-CENTRED CARE AND A STRENGTHS-BASED APPROACH

Family-centred, strengths-based care is an innovative approach to child health care grounded in a mutually beneficial partnership between the child, the family and the health care provider, and recognizes the importance of the family in a child's life.(15)

This approach involves building a trusting relationship and collaboration with the family, acknowledging the family's perspective and priorities, and regarding them as equal partners in delivering care to the child. By following this approach, health care providers can learn about the strengths of the child and the family, and the family can rely on the health care provider to support them in overcoming the negative impact of any developmental difficulties. (16)

The developmental monitoring process values the building of partnerships with families. This means that health care providers should demonstrate warmth and genuine interest in the child and the family, and work towards building a relationship based on transparency and partnership. Referring to the child and family by their names is important, while anything that interferes with eye contact and communication should be avoided, such as a desk or a computer.

Health care providers should make an effort to use words, phrases and expressions that the family can understand. The family should also be given opportunities to ask questions. Paying attention to the child, encouraging the child to play with toys or materials, observing what the child is doing, noticing how the child and family



STANDARD OF CARE

Health care providers need to build partnerships with families and apply principles of family-centred care during routine service provision.

Health care providers should apply principles of strengths-based care. Specifically, they should learn about the strengths of children and families and use them to maximize the child's developmental potential

Health care providers should make an effort to use words, phrases and expressions that the family can understand.

are interacting, and praising positive interactions are other things that health care providers can do to foster partnership. Acknowledging the family's perspective, beliefs and priorities when delivering care to the child is another important aspect. This means accepting the family as they are, respecting their cultural background and considering their priorities when making plans.

Current state of implementation

It is hard to know the current state of family-centred ECD-related services in Europe and Central Asia. Unfortunately, it remains a poorly studied subject. The responses to UNICEF's survey questions imply that family strengths and needs are not consistently assessed as part of developmental monitoring across the region (Q13). When asked if primary health care providers were considering parental concerns and perspectives during the developmental monitoring process (Q28), five out of eight survey participants responded "at some point", before further clarifying that "not all health care providers have skills", "there is still a wait and see approach and the lack of family-centred approach", and "not always, depending on knowledge and skills of parents and health staff". These responses point to inconsistencies in attending to parental concerns and suggest that there might be deficiencies in the delivery of family-centred care in primary health care.

The findings from the situational analyses reveal further deficiencies across multiple aspects of family-centred care in early intervention services, such as the family-friendliness of the waiting area,(17) the participation of parents during developmental assessments,(17, 18) cultural responsiveness,(19) difficulties in scheduling an appointment and stigmatization.(17, 19) Collectively, these findings indicate room for improvement.

B. INFORMING FAMILIES ABOUT THE IMPORTANCE OF EARLY BRAIN DEVELOPMENT

Research has shown that mothers of young children may lack information on early childhood development, leaving them unprepared to support their children's development during this critical period. (20) As primary health care providers are strategically placed to help families support their children during their most critical period of development, they have a very powerful role in informing families about the importance of early child development, brain plasticity and a child's need for early learning opportunities.

Current state of implementation

Systematic assessments have reported deficiencies in the preparedness of health care providers to advise families on their child's development.(6, 17, 18, 21) Addressing these deficiencies and creating opportunities for health care providers to deliver this component of developmental monitoring should be a priority.

The skills and attitudes required to deliver this task can be attained with the appropriate professional training. This topic needs to be covered as early as possible during the training process as a part of a holistic curriculum.

Primary health care providers have a very powerful role in informing families about the importance of early childhood development.



STANDARD OF CARE

Health care providers should inform families about the importance of early child development and brain plasticity, and provide recommendations on how they can support their child's development.

C. ASKING FAMILIES ABOUT THEIR CONCERNS REGARDING THEIR CHILD'S DEVELOPMENT



STANDARD OF CARE

Health care providers should ask families about their concerns regarding their child's development

Asking families about their concerns regarding their child's development is a crucial aspect of developmental monitoring. Parental concern about their child's development is an indication of developmental delay until proven otherwise. In practice, a simple question such as, "Do you have any concerns regarding your child's development?" is best asked in a semi-structured interview with the parent about the child's development. Families may frequently mistake development for physical growth, which means it is important to explain exactly what 'development' means. In the right context, the question invariably leads to caregivers sharing their observations on their child's development.

Implementing standardized developmental monitoring tools that include a question eliciting familial concerns about the child's development may ensure this question is consistently asked.

Current state of implementation

Asking about parental concerns is a simple and powerful strategy, but the available information points to the fact that even a question as straightforward as "Do you have any concerns regarding your child's development?" might not be systematically asked. Less than half of the survey's respondents (Q28) replied that primary health care providers were considering the parents' concerns and perspective in developmental monitoring. When developmental concerns are not acknowledged, developmental difficulties are not diagnosed in time, and children do not receive the required support when they are most likely to benefit from it. This may partly explain why more than half of children whose parents suspect they have a developmental difficulty do not receive a diagnosis or access to necessary services within one year, as evidenced by a situational analysis from Bulgaria.(18)

Parents say they need to exert tremendous effort to "get the attention of the health care provider" and be referred for services.(19) This is backed up by situational analyses from Croatia and North Macedonia, which captured the fact that parents often end up involved in early intervention programmes because they are proactively asking for services and not because they were referred from the health system. (19, 22)

Parental concerns are not being systematically elicited by professionals; it is families who first suspect their child's difficulties, demand services and initiate the referral.

D. LEARNING ABOUT THE NURTURING CARE ENVIRONMENT

A nurturing care environment represents all the early learning opportunities available to a child. This involves learning about routine activities that family members already do to support their child's development and learning, such as reading books or singing songs. In practice, a simple question such as, "What are the things that you and your family are doing to support your child's development and learning?" can be asked in order to learn about the family's approach to nurturing care. It is very important to praise families for what they are already doing. Health care providers should also identify whether the care provided is appropriate – for example, whether the activities or methods of discipline are suitable.

Current state of implementation

The survey did not specifically inquire about implementing this aspect of developmental monitoring.



STANDARD OF CARE

Health care providers should learn about the nurturing care environment of the child and how families are already supporting their child's development.

E. LEARNING ABOUT RISK FACTORS THAT IMPEDE DEVELOPMENT AND HOW FAMILIES COPE



STANDARD OF CARE

Health care providers should learn about the risk factors that impede development.

Health care providers should learn about the coping strategies that families use and the available resources.

Learning about developmental risks is an important and integral aspect of developmental monitoring. While developmental risks can be health-related or psychosocial, they frequently occur together and affect a child's development through multiple complex pathways.

Some of the most common risks that can affect children during their earliest years include inadequacies in the nurturing care environment, physical and mental health problems of the caregiver, undernutrition, problems related to the perinatal and newborn period, such as low birth weight, micronutrient deficiencies or chronic illness. Life-cycle approach is a useful way to look at developmental risk factors.⁽⁸⁾ In this approach, health care providers consider developmental risks in order of their appearance and significance within the life cycle. For example, caregiver mental health problems should be actively sought and addressed even before the child is actually born, for example, during antenatal care.

Health-related risks can be identified through medical health records and routine medical examinations. In many countries, health-related risks are routinely addressed via public health measures already in place, such as neonatal screening or immunizations. Psychosocial risks can be identified using interviews and observational skills. For example, health care providers may learn about psychosocial risks by asking families, "Sometimes caregivers have a lot going on. They may feel overwhelmed, stressed or depressed, and there may be financial problems or illness in the family. Supporting their child's development may be difficult. Are there any such difficulties in your family?"

It is very important that health care providers systematically seek out and address any identified risks. The use of specific screening tests for the identification of common psychosocial risks is encouraged (for example, the Edinburgh Postnatal Depression Scale for maternal depression). Societal stigma is another important factor that may affect development by restricting early learning opportunities. Health care providers should try to learn about how to help families cope with stigma. They should also assess whether families have the resources to confront the risks that they face. For example, they could follow up with the question, "At this early age when development is so important, what could you, your family, friends and community do to help your child develop despite these difficulties?" This information is important in order to come up with a realistic plan to support the child's development.

Current state of implementation

The Developmental Difficulties in Early Childhood Survey encompassed many countries from ECAR and was conducted over a decade ago. The survey identified that, in 43% of the surveyed countries, most health care providers had received some training and experience in using interviews and observational skills to identify health-related risk factors, but in only 12% of countries had health care providers received training and experience in using interview and observational skills to identify psychosocial risks.(6)

The responses to Q11 in the present survey indicate that assessments of health-related risks, the family's strengths and needs, and psychosocial risks are still not uniformly implemented across countries. The in-depth interviews also suggest that the assessment of psychosocial risks may not be a systematic practice and may depend on the professional. Most regional countries have already attained high immunization rates, preventing many health-related risks. Yet the survey's responses indicate that some countries are still to attain universal coverage via neonatal screening for commonly encountered and treatable health-related risks such as hypothyroidism, hearing loss and vision loss.

Assessments of health-related risks, the family's strengths and needs, and psychosocial risks are still not uniformly implemented across countries.



STANDARD OF CARE

Health care providers must use standardized and validated developmental monitoring tools to assess the child's development at regular intervals at least once at around 9, 18, 24 and 36 months for typically developing children, and whenever the caregiver raises a concern.

Health care providers should use standardized, validated tools for developmental monitoring to talk with the caregiver about the child's development and to support the child with individualized recommendations – they should not use these tools to solely 'screen and refer'.

The administration of a standardized developmental monitoring tool at regular intervals should be universal, that is, applied to the entire eligible paediatric population.

F. UNIVERSAL ADMINISTRATION OF STANDARDIZED AND VALIDATED TOOLS FOR DEVELOPMENTAL MONITORING

Implementing the use of a standardized tool remains one of the most urgent aspects of developmental monitoring, and one of the most challenging. Other components of developmental monitoring, such as clinical judgement, eliciting caregiver concerns and observations, and the assessment of developmental risks cannot replace the proper administration of standardized and validated developmental monitoring tools. Previous research has consistently shown the inadequacy of clinical judgement alone in identifying commonly occurring mild developmental delays.(23, 24)

The suggestion to administer standardized tools for developmental monitoring at the ages of 9, 18, 24 and 36 months is similar to the official position statement of the American Academy of Pediatrics. This professional organization suggests administering a standardized, validated developmental screening tool at 9, 18 and 30 months of age, and also recommends administering an autism-specific tool at 18 and 24 months of age.(25)

In practice, the administration of standardized, validated tools for developmental monitoring may require slight deviations from these ages. Countries should seek to identify opportunities within their existing routine schedule of child primary health care visits which coincide with these ages as closely as possible to ensure a high coverage of the eligible population. These ages (or age intervals) should be explicitly articulated in the documents mandating the use of standardized tools.

The suggested ages for the administration of standardized and validated tools for developmental monitoring for typically developing children are not arbitrary but coincide with the ages when commonly occurring developmental disabilities can be reliably identified. For example, a child who is not sitting by the age of 9 months may be diagnosed with cerebral palsy, or a child with delayed language and socio-emotional skills may be diagnosed with autism by 18 months – early enough to benefit from effective early intervention. Subtle language delays that have not caught the caregiver's attention earlier will become fully manifest by 30–36 months of age and will be identified by standardized tools. Because these developmental difficulties may subtly manifest themselves even earlier, the use of standardized developmental monitoring tools should be considered whenever the caregiver suspects problems.

Standardized tools for developmental monitoring should be applied universally – that is, to all children. If applied selectively, children with

mild developmental difficulties or whose parents have no concerns despite difficulties may 'fall through the cracks' of the system and go unnoticed.

Additionally, paying close attention to the developmental skills necessary for school readiness is very important at 4 or 5 years old. Health care visits at this time should be used to identify previously unrecognized problems.(25) The American Academy of Pediatrics does not currently recommend using a standardized, validated tool for developmental monitoring at the 4- or 5-year visit for typically developing children. Physical health, social and emotional development, learning and motivation to learn, attention, language development, cognition and general knowledge should, however, be monitored and supported.(25, 26) Health care professionals should use appropriate standardized, validated tools whenever concerns are identified.

Current state of implementation

The Developmental Difficulties in Early Childhood Survey revealed that in most countries most health care providers were not routinely using standardized tools for identification of developmental difficulties.(6) The current survey (Q8) asked respondents to indicate what approaches health care professionals use when monitoring child development, with the following options: clinical assessment, observation, a list of developmental risks and a standardized tool. Slightly more than half of the respondents indicated using a standardized tool as the basis for developmental monitoring.

Consistent with the above, findings from the situational analyses in countries across the region also support the argument that the use of standardized tools for developmental monitoring is, at best, partial. (18, 22, 27) Studies from high-income countries also report that only about a third of eligible children are being monitored using a standardized tool.(28, 29) Further, situational analyses suggest that parental concerns about their child's development may not always result in the administration of a standardized, validated developmental monitoring tool.(18)

The survey responses (Q12) also suggest that there is no clarity on the optimal age when standardized developmental monitoring tools should be used in primary health care.

The universal administration of standardized developmental monitoring tools may not be happening in countries which are yet to build a system of universal developmental monitoring, such as Montenegro or North Macedonia (22, 30) or in circumstances when the administration of a standardized tool is conditional to being screened as positive on a red-flag list, or upon parental concern. For example, in Belarus, standardized tools for developmental monitoring are systematically

Implementing the use of a standardized tool remains one of the most urgent aspects of developmental monitoring, and one of the most challenging.

applied when a child is referred by a physician or self-referred by the parent to the district early intervention facility. Even in countries where the universal use of such tools has been introduced and encouraged, it may be difficult to sustain their consistent use across facilities, within one facility or even by the same professional. The COVID-19 pandemic has shown that important but non-urgent services, such as ECD, may quickly become neglected when priorities shift.(31)

The survey (Q11) also inquired about barriers to using standardized developmental monitoring tools: the most cited barriers were time constraints and a lack of trained staff. Other barriers included the cost of the tools, a lack of access to appropriate tools, the absence of formal requirements and a lack of funding and guidance at the country level. Recently published seminal reports, situation analyses and testimonies of professionals working in the field consistently repeat the same barriers in a nearly identical order.(6, 17, 18)

The following sections will present a detailed discussion of the steps that may help to overcome the most common barriers to developmental monitoring:

- Section 3.2 examines the lack of adequately trained staff
- Section 3.5 explores the lack of availability of standardized, validated tools
- Section 3.6 looks at the time constraints, lack of formal requirement and lack of guidance at the country level

G. SHARING INFORMATION WITH FAMILIES ABOUT THEIR CHILD'S DEVELOPMENT, AND HOW TO SUPPORT DEVELOPMENTAL DOMAINS

Sharing information about a child's developmental functioning, including strengths and difficulties and recommended actions on how to support the child's development is one of the most important aspects of developmental monitoring. Previous steps should enable the accumulation of relevant information that needs to be shared with the family.

Health care providers should always begin by emphasizing the child's strengths before they proceed to sharing difficulties. They can proceed to caregiver concerns next. It is very important that health care providers attend to the caregiver's concerns, even if the development appears age typical. In such cases, reassurance may be sufficient. If there is a need for support for development, the caregiver needs to be informed explicitly. The caregiver should be provided with specific examples of what the child has already attained and their next attainment goals. The recommendations for a child and a family should be individualized and be informed by World Health Organization International Classification of Functioning, Health, and Disability (ICF).^(32, 33) Developmental support recommendations should focus on promoting functional skills, prioritize routines such as play, home chores, spending time in nature, engagement in relationships within family and community, and take into account personal interests of the child, as well as contextual factors related to the family.⁽³³⁾ Parents should leave the professional with a firm knowledge of what they should and should not be doing at home.

When providing feedback, it is crucial that health care providers ask families' opinions about possible causes for developmental difficulties. The family's perception of the child's development is very important and may guide health care providers in planning for follow-up, consultations, laboratory investigations and referrals for early intervention services. These plans should be made together with the families. Health care providers should make sure the caregivers fully comprehend everything that is being said; otherwise valuable time may be lost due to misunderstanding, denial of the diagnosis or non-compliance, and health care providers should avoid these scenarios at all costs. Health care providers should be knowledgeable about the existing evidence-based services in the community and be able to guide families seamlessly to these services.



STANDARD OF CARE

Health care providers share information about the child's developmental functioning with the caregivers, including strengths and difficulties. Health care providers should also be able to share recommendations on how to support the child's development.

Health care providers should be knowledgeable about evidence-based services in the community and be able to guide families to these services.

Reports from across the region suggest that health care providers may not be adequately prepared to share information with caregivers about their child's development.

Current state of implementation

There is a large body of literature providing evidence that disruptions in the continuity of developmental monitoring frequently occur at the point when health care providers should be sharing information with caregivers. Reports from across the region suggest that health care providers may not be adequately prepared to share information with caregivers about their child's development.(6, 17, 18, 21) They may not be placing emphasis on communicating the strengths of the child; they may be informing the caregivers only about the child's difficulties; or they might be using stigmatizing language or medical jargon. As a result, caregivers may struggle to accept their child's difficulties.(18)

The health care provider may also be hesitant about whether or not the child has a delay and how to communicate this uncertainty to the caregivers. This may result in discomfort when sharing the results of developmental monitoring or fear of identifying developmental difficulties.(34) Health care providers may end up ordering additional tests or investigations if they are unsure. In the end, caregivers and parents may become confused by conflicting advice and opinions, which may lead to burnout and fatigue, precluding their ability to support their child's development.

The systemic reasons for disruptions at this stage, such as lack of appropriate training and lack of time, will be addressed in the following sections.



KEY RECOMMENDED ACTIONS FOR HEALTH SYSTEMS AND PROFESSIONALS ON ESSENTIAL ELEMENTS OF DEVELOPMENTAL MONITORING

APPLYING PRINCIPLES OF FAMILY-CENTRED CARE

- Adopt a family-centred, strengths-based approach as a standard of care in paediatric health care provision.

INFORMING FAMILIES ABOUT THE IMPORTANCE OF EARLY BRAIN DEVELOPMENT

- Make sure health care providers inform families about the importance of early child development and brain plasticity, and provide recommendations on how they can support their child's development.

ASKING FAMILIES ABOUT THEIR CONCERNS REGARDING THEIR CHILD'S DEVELOPMENT

- Make sure health care providers elicit caregivers' concerns regarding their child's development during encounters with the health care system.

LEARNING ABOUT THE NURTURING CARE ENVIRONMENT

- Make sure health care providers learn about the child's nurturing care environment and how families already support their child's development.

LEARNING ABOUT RISK FACTORS THAT IMPEDE DEVELOPMENT AND HOW FAMILIES COPE

- Make sure health care providers learn about the risk factors that impede development, and learn about the coping strategies that families use – as well as the resources they have available to them.

UNIVERSAL ADMINISTRATION OF STANDARDIZED AND VALIDATED TOOLS FOR DEVELOPMENTAL MONITORING

- Mandate administration of standardized, validated developmental monitoring tools at least once at around 9, 18, 24 and 36 months for typically developing children, or whenever a caregiver elicits developmental concern.
- Take steps to implement the universal administration of standardized, validated developmental monitoring tools at regular intervals. Make use of routine well-child visits. Explore the opportunities to administer the tools during home visits.
- Ensure the proper administration of standardized, validated developmental tools.
- Ensure that health care providers provide individualized recommendations on how to support the child's development. Avoid a 'screen and refer' approach.
- Health care providers should pay close attention to the developmental skills necessary for school readiness at around 4–5 years of age to identify problems not previously recognized, and should use the appropriate standardized, validated tools whenever concerns are identified.

SHARING INFORMATION ABOUT THE CHILD'S DEVELOPMENTAL FUNCTIONING, STRENGTHS AND DIFFICULTIES, AND PROVIDING RECOMMENDATIONS ON HOW TO SUPPORT THE CHILD'S DEVELOPMENT.

- Ensure that health care providers share information with caregivers about the child's developmental functioning, strengths and difficulties, and provide individualized recommendations on how to support the child's development.
- Ensure that health care providers are knowledgeable about evidence-based services in the community and can guide families to these services.

3.1.2 | INTEGRATION OF DEVELOPMENTAL MONITORING IN HEALTH CARE

Health care providers should have child development on the agenda every time they encounter the child and family, in the same way that the child's growth is addressed at every scheduled check-up. As ambitious as this may sound, this does not mean that providers should devote the same amount of time and effort during each encounter. Some age intervals will require administration of standardized validated tools for developmental monitoring along with the provision of all components of developmental monitoring.(6, 25) On other occasions, health care providers may suffice with sharing information on supporting early development, asking about parental concerns, addressing any pending issues or being alert to newly emerging risks.(6) By keeping a constant focus on developmental monitoring, health care providers will be able to accumulate a wealth of information about the child and the family, and this will allow for the flexibility to address time constraints.(6)

The optimal conditions for conducting developmental monitoring arise when children are brought for immunizations or well-child visits. This is because these occasions are predictable, and there is generally no competing agenda. Home visits are another good opportunity, especially when developmental monitoring can be conducted in conjunction with addressing mental health of the parents, encouraging them to provide early learning opportunities or helping to recognize risks for optimal development in the home environment. Mental health issues are very common and may occur at all stages of human life, thus it is important to actively look for and address them during family planning, antenatal care and postnatal visits.

Our knowledge about early childhood development and the considerable burden of developmental difficulties calls for the prioritization of universal developmental monitoring. 'Universal' means that all children and families receive developmental monitoring during routine contacts with health care providers. This also involves the universal administration of brief standardized and validated developmental assessment tools. (This is discussed in greater detail in Section 3.1.1.)

Ease of access and comprehensive coverage by the primary health infrastructure are also crucial in ensuring universal developmental monitoring. These will be reflected through the geographical proximity of health facilities, availability of affordable transportation and overall coverage by essential services, such as immunization.



STANDARD OF CARE

Developmental monitoring should be an integral part of every well-child visit and should be well-integrated into the services provided at the primary health care level.

Developmental monitoring should be universally available.

Current state of implementation

The different levels of integration of developmental monitoring within national health care provision is reflected in the survey responses (Q7).

In this sample of countries, developmental monitoring was reported to be integrated in the following scenarios (in decreasing order of frequency):

- As a part of facility-based well-child visits
- During check-ups linked with immunization services
- Within distinct facility-based check-up visits, scheduled only for developmental monitoring
- During home visits
- Within ECD or other counselling services at the PHC level
- During sick-child check-ups
- Only at higher referral levels (secondary or tertiary health care) following referral from PHC

Apart from the final point, all of these opportunities represent services provided within primary health care.

The goal of universal developmental monitoring is not being achieved despite the fact that most of the survey respondents regarded developmental monitoring as standard practice within primary health care (Q3). Other sources of information indicate that coverage is far from universal and that practices are not aligned with the essential components of developmental monitoring (such as using standardized, validated tools).

If developmental monitoring is applied selectively, many children with developmental difficulties will go unnoticed.

Only 12% of parents participating in a situational analysis of early intervention services in Bulgaria reported ever receiving services related to child development, even though national legislation legally requires health care workers to provide such services.⁽¹⁸⁾ Similar situation analyses from Montenegro and North Macedonia also indicate that developmental monitoring is not universally available.^(22, 30) In other countries, such as Belarus, developmental monitoring has been introduced, but it cannot be considered universal because child development is addressed systematically only when the child is referred to a specialized facility within primary health care or higher levels of health care.

If developmental monitoring is applied selectively, many children with developmental difficulties will go unnoticed. They will only be identified at later ages when they fail to attain school readiness, meaning that the opportunity to intervene early has been missed. With this in mind, it is essential that all of the eligible paediatric population is covered by quality, accessible developmental monitoring.

Overall, in this sample of countries, the primary health care infrastructure was generally accessible and within walking distance or

reachable by affordable transportation (Q28). Immunization rates are also typically high,(35) indicating adequate coverage by primary health care services in ECAR. Also, 80% of European Member States have a system of home-visiting nurses and midwives.(12) Thus, the accessible infrastructure, high coverage of primary health care services, and availability of home-visiting can be seen as strengths in the regional health systems with respect to developmental monitoring.



KEY RECOMMENDED ACTIONS FOR HEALTH SYSTEMS REGARDING THE INTEGRATION OF DEVELOPMENTAL MONITORING

- Health systems should explore opportunities to integrate developmental monitoring within existing service delivery. The optimal conditions for conducting developmental monitoring arise when children are brought for immunizations or well-child check-ups. Exploit the opportunity to introduce developmental monitoring within the home-visiting system, where it exists.
- Health systems should include child development on the agenda of every routine health check-up visit and provide providers with sufficient resources to address child development during these visits.
- Health systems should aim to deliver developmental monitoring universally to all preschool-age children.



CASE STUDY

The recently published World Health Organization Pocket Book of Primary Health Care for Children and Adolescents outlines evidence-based standards of health care and aims to unify approaches in primary health care across the WHO European region.(36)(REF) Well-child visits and Health Promotion and Disease Prevention sections of the pocketbook provide optimal content of well-child visits where focus on early childhood development and developmental monitoring is integral part of every visit. More specifically, the Pocketbook provides short guidance to primary health care providers suggesting that they should “monitor development, support child’s development and determine if there are any areas that need extra support, identify and address risk factors for developmental difficulties and deal with developmental difficulties when they manifest”.

The Universal Health Visiting Pathway in Scotland is an example of a home-visiting programme from a high-income country which has succeeded in introducing a more comprehensive range of services, including universal developmental screening (along with the assessment of maternal and family well-being and mental health, promotion of positive infant–mother attachment, physical health promotion including nutritional support and immunizations, sharing of public health information and community resources, and the assessment and addressing of psychosocial risks such as poverty, alcoholism or violence.(37) The programme offers at least 11 routine visits by the time the child is 5 years old.

3.1.3 | FOLLOWING UP ON CHILDREN WITH RISKS, DELAYS OR DISABILITIES



STANDARD OF CARE

- Public health programmes, such as neonatal screening, should have referral and follow-up protocols in place to ensure that children with identified issues or risks are provided with referrals or links to appropriate health care facilities for developmental monitoring.
- Health care providers should also consider developmental monitoring in cases where knowledgeable professionals from other sectors, such as education or social care, raise concerns about the child's development.
- Whenever risks, delays or disabilities are identified, health care providers should immediately provide recommendations to the caregiver on what they should be doing at home to continue supporting their child's development, what needs to be done to address the identified risks, and how they can connect to the services that will support them.
- Health care providers should refer children with risks, delays or disabilities for a comprehensive, family-centred developmental assessment whenever indicated.
- The comprehensive developmental assessment of young children should incorporate key elements to ensure quality.

Early identification should be everyone's responsibility.

Early identification should be everyone's responsibility. It is true that health care systems may already have routine programmes (such as neonatal screening or antenatal care) that will result in the identification of children with developmental risks. But aside from these unique opportunities within health systems, knowledgeable professionals in other sectors who regularly see young children and/or their families also have their role in developmental monitoring. The existence of formal links between the health care and education systems (upon concerns from a professional in nurseries, kindergarten and preschools) or the social welfare system (upon identification of environmental risks, abuse and neglect and extreme poverty) is a very important aspect of an early identification system. When not present, such links should be established.

Health care providers need to share information about the available services that can support children with identified risks, delays or disabilities and their families. Health care providers should always share individualized recommendations to support a child's development, and families should leave the professional with a firm knowledge of what they should and should not be doing at home. Health care providers need to share information on the child's strengths, the domains of development that need support, the identified risks, what needs to be done to address the identified risks, and how they can connect families to the services that will support them. Health care providers should be knowledgeable about locally available resources and support. Health care providers should avoid waiting for laboratory tests or consultations to share information on how to support a child's development. This is especially important because caregivers may have to wait for a long time before tests are carried out or consultations are conducted, or before the child can be connected to services.

Children and families should be smoothly connected with the relevant services. The health system and professionals conducting developmental monitoring should be familiar with the evidence-based services available in the local community so that they can refer the family and ensure follow-up. The ultimate goal of monitoring is to support the child's development and start providing early intervention immediately after the need is established, and not to wait until the child can start a formal early intervention programme.

A comprehensive, family-centred developmental assessment should be undertaken for every child with identified risks, delays or disabilities to establish a specific diagnosis, identify the needs of the child and family for additional support and services, and link the child and family to such services.

A comprehensive developmental assessment (CDA) differs from the brief assessments of child development that primary health care

Health care providers should avoid waiting for laboratory tests or consultations to share information on how to support a child's development.

A COMPREHENSIVE DEVELOPMENTAL ASSESSMENT (CDA) OF YOUNG CHILDREN INCLUDES:

- **Family-centred, strengths-based care**
- **A detailed developmental history**
- **Attention to the caregivers' concerns**
- **Use of developmental assessment tools for a holistic assessment of development**
- **Observations of the child's interactions with the caregivers**
- **Assessment of nurturing care provided in the home environment**
- **Social support for the caregivers and family, including for their mental and physical health**
- **The provision of seamless links to early intervention services**

providers typically conduct in the context of developmental monitoring, although the same principles are applied. A CDA allocates more time and is more detailed.

A CDA can be conducted by a single professional or a team of professionals with various backgrounds (such as developmental behavioural paediatrics, paediatric neurology, child psychiatry, early intervention, child psychology, child development, audiology, speech therapy, special education, occupational therapy, physiotherapy and rehabilitation, ophthalmology, orthopaedics, or clinical genetics). A CDA should combine the expertise of every professional in a joint report which captures the child's developmental functioning, plus the unique needs of the child and family that need to be addressed.(6) A fragmented assessment in which different professionals separately evaluate children to produce several different reports should be avoided.(6)

Current state of implementation

The survey (Q20) asked respondents about the formal referral pathways to primary health care for developmental monitoring from other places, such as prenatal services (in the case of prenatal or genetic risks), perinatal services (upon prematurity and neonatal complications), the education system (upon a professional's concerns in nurseries, kindergarten and preschools) and the social welfare system (upon environmental risks, abuse and neglect, and extreme poverty). In this sample of regional countries, only half were reported to have all four links in place, while in other instances there were combinations of links or no formal links at all.

Support services: The findings of the survey (Q15) suggest that in the surveyed countries, health systems do offer different combinations of family counselling, referral to early childhood intervention services, interviews with caregivers, re-evaluation after a defined period of time, home visits, referral to a medical examination commission and referral to a secondary- or tertiary-level hospital whenever risks, delays or disabilities are identified.

Parental counselling: Situational analyses have uncovered that parents lack knowledge about the early intervention services available to them, and that primary health care professionals are not well-prepared to advise parents on how to access these services.(17-19, 22) In some countries the only action that care providers take after identifying developmental difficulties is to refer the child to higher levels of health care or early childhood intervention (ECI) services where available. This is particularly worrying because such an approach may leave caregivers completely oblivious to the child's condition, or they may be confused about what they should do to support the child's development while

Situational analyses have uncovered that parents lack knowledge about the early intervention services available to them.

waiting for the services to start. Lack of adequate parental counselling, together with limited availability of early intervention services, results in parental anxiety, delays in connecting to services and an overall failure to provide much-needed support.(17-19, 22)

Capabilities for a **comprehensive developmental assessment** (CDA) do exist in the countries covered by the survey (Q16), however, they may still be lacking in other countries.(30) For a CDA, a referral to another facility within the boundaries of primary health care or to higher levels of health care (Q17) is required, and the usual waiting time (Q18) is in the range of a few weeks to three months.

Having the capacity to conduct a CDA is a strength. However, both the survey responses and the situational analyses of ECI in Serbia and North Macedonia show that about 15–24% of children destined for a CDA do not actually receive an assessment. When children do receive a CDA, the assessments are of variable quality and are not consistent, even within the same country.(17, 22)

The situational analyses show that despite a health system having the capacity for CDA, its core principles, such as family-centred care, may not always be met. For example, most of the surveyed parents whose children were attending early intervention services in North Macedonia reported that they did not participate in a CDA, and did not know how it was conducted nor which tests were used.(22) Parents consistently reported being left out of the further steps that happen after CDA, such as the writing up of outcomes for individualized family service plans and the actual provision of early intervention services.(17-19, 22, 30) There is a lack of information about whether other core CDA components are being implemented using a family-centred framework, but there are reasons to assume that they are not.

The Developmental Difficulties in Early Childhood Survey found out that, in most low- and middle-income countries, a paediatrician conducted developmental assessments and decided which kinds of early intervention or rehabilitation services the children should receive.(6) The seminal report on the findings of this survey points to a discrepancy between developed and developing countries in respect of the teams of professionals available for CDAs.(6) Developing countries have fewer resources and, as a result, only one or a small number of professionals may be available to carry out CDAs. The same finding appears in the present survey. Respondents reported that specialists, such as neuropaediatricians, paediatricians, special educators, orthopaedics specialists, physical medicine and rehabilitation physicians, and social workers were available to carry out CDAs in their countries. Psychologists, speech therapists, occupational therapists and psychiatrists were also reported to be available upon invitation.

Developing countries have fewer resources and, as a result, only one or a small number of professionals may be available to carry out CDAs.

In a situational analysis from North Macedonia, half of the surveyed parents reported being assessed by different professionals at different times.(22) This implies that, for the time being, where CDAs are available, the predominant model is still a fragmented assessment.



KEY RECOMMENDED ACTIONS FOR HEALTH SYSTEMS REGARDING FOLLOWING-UP ON CHILDREN WITH RISKS, DELAYS OR DISABILITIES

- Establish formal links across the health care system as well as between health care and other sectors, to enable developmental monitoring for children with identified risks or for whom concerns have been raised by professionals in the health care, education or social welfare sectors.
- Ensure that children with risks, delays or disabilities and their families receive individualized developmental support immediately upon identification. Avoid deferring the support until tests, laboratory consultations or eligibility for services are established.
- Meet the information needs of families during their most vulnerable period when developmental risks, delays or disabilities are identified for the first time.
- Make sure health care providers are knowledgeable about the evidence-based services available in the local community and can advise families about how to access them.
- Increase capacity for family-centred, strengths-based integrated comprehensive developmental assessments.

3.1.4 | SUPPORT THROUGH EARLY CHILDHOOD INTERVENTION

The term 'eligibility criteria' describes a common set of rules to determine which children qualify for enrolment in early intervention services. There may also exist eligibility criteria for other benefits, such as financial support, discounts on goods and services (e.g., public transportation), tax reductions or waivers, etc. Setting such criteria in the context of the National ECI Programme is important for unifying approaches across the country.

Eligibility criteria should be comprehensive, inclusive and flexible, allowing children with developmental risks, delays and disabilities to participate in early intervention in a timely and equitable fashion. Often, children may not qualify for early intervention because the criteria are too restrictive. This may happen when these criteria are laid out using a medical model of disability, which means that 'purely' medical conditions, such as congenital hearing loss or Down syndrome, qualify a child for early intervention. With such criteria, a large proportion of children with mild-to-moderate developmental difficulties due to health-related risks such as prematurity or low birth weight, or with psychosocial risks such as poverty, will be regarded as ineligible for preventive early intervention services.

Unlike a medical model, a social model views developmental difficulties through the lens of biological and environmental constraints that must be addressed in order to promote development.⁽³⁸⁾ In practice, this means that a comprehensive developmental assessment should include assessment not only of the child's developmental profile, but also of the diverse needs of the child and family. Input from the health care, education and social welfare sectors should be merged in order to assess the needs of children with developmental difficulties and their families in a holistic manner, and then decide on the child's eligibility for services and benefit allowances. If only the health care sector is tasked with defining the level of support for which the child and family are eligible, they may not get all the support they need.

The preferred model of care in contemporary early intervention is a transdisciplinary model, where one or more professionals use a common conceptual framework to conduct the comprehensive developmental assessment, produce a single report that captures all aspects of the assessment, and deliver early intervention. In this model, one professional takes the responsibility for case management and coordination, and consults colleagues on matters that transcend the professional's expertise. With time, professionals are able to share roles and learn from each other.



STANDARD OF CARE

The eligibility criteria for participation in early intervention services should be inclusive, comprehensive and flexible to allow children with developmental risks, delays or disabilities and their families to access early intervention services in a timely and equitable fashion.

Contemporary early childhood intervention should be accessible, affordable and community based, and delivered to children and their families by transdisciplinary teams in the child's natural environments.

Situation analyses also point to an unacceptably long interval between the first identification of developmental difficulties and when eligible children actually start to receive services.

Current state of implementation

Eligibility criteria were not uniformly present across the countries where systematic assessments were conducted. Establishing universal eligibility criteria for participating in ECI services consistently appears as a major recommendation of ECI experts for Croatia, Montenegro and North Macedonia.(19, 22, 30) Other concerns about the existing eligibility criteria were also cited, namely: the criteria were not uniform, not comprehensive or not based on a social model of disability; a lack of knowledge about such criteria appeared as a major barrier to accessing services for children with developmental difficulties and their families; and an assessment of the programme's eligibility criteria was not taken into account when deciding on the funding support for this programme.(17, 19, 22)

Timeliness of early intervention. Situation analyses also point to an unacceptably long interval between the first identification of developmental difficulties and when eligible children actually start to receive services. A formal diagnosis is needed to start early intervention, which is another important systemic barrier.(22) But even children diagnosed relatively early with well-known conditions that result in significant developmental problems (such as Down syndrome) may still have to wait for a formal assessment to be able to access early intervention. By this time, the intervention is no longer early. With this in mind, experts recommend using a functional assessment to help determine eligibility and inform early intervention rather than waiting until a definitive diagnosis is established.(17) They also recommend avoiding reliance on a small number of decision-makers who can determine if the child is eligible.(17) There appears to be a significant bottleneck preventing access to early intervention services, which urgently needs to be addressed.

Overall, transdisciplinary care is newly evolving in the European and Central Asian region, although at a different pace in different countries. For example, in North Macedonia, only 6% of the existing early intervention centres had adopted this model by 2022.(22) This is in contrast to Croatia, where 29% of the early intervention centres have evolved to become transdisciplinary by 2020.(19) In the meantime, parents of children with developmental difficulties often report having to move their child around because different services/professionals are not available in one location.(17)



CASE STUDY

Eligibility for ECI services in Portugal can be used as a blueprint for defining national eligibility criteria. Within the Portuguese National ECI System, services are provided to all children 0–6 years old and their families who have medical conditions (not necessarily with a definitive diagnosis) resulting in a suboptimal developmental trajectory and limitations in activities and participation, or four or more biological, psychosocial or environmental risk factors.(39) While the definition of ‘medical conditions’ is very straightforward, including ‘children at risk of developmental delay’ among eligibility criteria is particularly illustrative of an inclusive approach to involving children in the ECI programme.



CASE STUDY

In 2019, Türkiye adopted a new regulation on disability for children and youth which is based on a social model, called Special Needs Certificate for Children and Youth.(40) This was a breakthrough after decades of advocacy by academia, civil society and clinicians, led by Dr Ilgi Ertem at Ankara University, School of Medicine, Paediatrics Department, Developmental Paediatrics Division. The new legislation addressed the inadequacies of the former medical model-based ‘Disability Health Council Certificate’.(41)

Previously, ‘disability ratios’, calculated using an idiosyncratic formula, formed the basis of a child’s eligibility for services and benefits. The hallmark of the new regulation is that the basis for eligibility for services is formed by the needs of the child and family. Also, the new legislation is specific to children, uses non-stigmatizing terminology and addresses systemic barriers that used to result in long waiting times. It also improves the certification process by adding flexibility and envisions the involvement of the child’s attending physician in the certification council.



KEY RECOMMENDED ACTIONS FOR HEALTH CARE SYSTEMS ON SUPPORTING CHILDREN WITH RISKS, DELAYS OR DISABILITIES THROUGH THE EARLY INTERVENTION SYSTEM

- Continue the efforts to set up by national early intervention systems aligned with a social model of disability.
- Establish inclusive, comprehensive and flexible eligibility criteria for children with developmental risks, delays or disabilities to enable timely and equitable access to early intervention services.
- Make sure contemporary early childhood intervention is accessible, affordable, community-based and delivered to children and their families by transdisciplinary teams in the child’s natural environments.
- Ensure coordinated support from the health care, education and social welfare sectors.
- Use common conceptual frameworks to assess the unique needs of children with risks, delays or disabilities, and enable their access to a range of supporting benefits and services.

3.1.5 | COORDINATION AND COLLABORATION



STANDARD OF CARE

Formal intra-sectoral communication within the health system should exist to ensure a continuum of care and coordination.

Strong and efficient collaboration and coordination must exist to ensure integration across the various aspects of developmental monitoring and early intervention covered by different sectors.

Intra-sectoral communication is crucial to maintaining the efficient delivery of quality services related to developmental monitoring and to coordinate care across the health care system. Requesting a written report is a good means of ensuring a follow-up and is even better when coupled with contacting the receiving professional/institution. The referring professional may speak to the professional or organization to which the child has been referred. Such contacts are important for establishing bonds between different professionals caring for the same child.

In some high-income countries, professionals write formal referral letters when contacting the receiving professional/institution. The receiving institution then returns a similar written report to guide the primary health care provider on how the child and the family can be further supported. This practice requires agreed standards on writing a comprehensive referral letter, and the health system should allocate sufficient resources to accomplish the task.

Contacting the family to check if they have followed the health care provider's recommendations is also very important to continue forging a partnership between the primary health care provider and the family, and this also implies that the child is 'being kept in mind'.

Formal contact should not be the only means of securing follow-up. One measure that can help improve communication between professionals is to engage professionals from primary health care and upper levels of health care within the same in-service training sessions, or create opportunities for professionals to get to know the referral facilities through short-term rotations. Seeking solutions for setting up and improving formal intra-sectoral communication is also strongly recommended. Digital solutions and features within the health information systems may also be used as innovative approaches to ensure follow-up upon referral.

Inter-sectoral coordination and collaboration are essential in ensuring smooth support across different sectors for developmental monitoring and early intervention, based on the common principles and conceptual framework. The provision of developmental monitoring as a universal service requires the interaction of different agencies, of which health care is the most important. Other departments, such as education, social protection, finances, local governments and the non-governmental sector do, however, also have a role. This is because developmental monitoring involves many different aspects, while children with developmental difficulties (and their families) have many different needs, which are often served by different ministries.

Integrating different aspects of developmental monitoring across different sectors requires efficient coordination and collaboration, and families frequently identify this as a major concern. Issues might arise at any point during a family's journey, starting from identification, referral, comprehensive developmental assessment, granting eligibility for and receiving early intervention, and applying for and receiving benefits.

Current state of implementation

Intra-sectoral coordination: While formal communication across health care departments is desirable, a research paper exploring the differences in professional roles in developmental monitoring uncovered that formal communication may not exist even in the health systems of some high-income countries, where professionals within health care frequently communicate with each other informally through the family instead.(42)

Question 23 of the survey asked respondents how professionals would typically ensure follow-up upon referral to ECI services. The responses revealed that follow-up was poor. The majority of respondents indicated that a written report was requested following a child's referral. Some also reported that parents had been contacted to check if they had followed the recommendations. The survey (Q24) also revealed that intra-sectoral coordination may not be happening in the surveyed countries.

The survey responses indicate the deficiencies in coordination between providers of primary health care and early intervention services, and suggest issues such as delayed referrals, problems in tracking the referral outcomes, and an overburdening of tertiary care for children with disabilities.

Inter-sectoral coordination and collaboration show deficiencies at each stage of developmental monitoring and early intervention as evidenced by the survey responses (Q25) and the data from situational analyses.(17-19, 22, 30) For example, a survey of ECI programme directors from Croatia and North Macedonia revealed gaps in the coordination of referrals from services where developmental risks, delays or disabilities are commonly identified, for example neonatal intensive care units, health centres, hospitals or nurseries/childcare centres.(19, 22)

A lack of information about the various services available from different agencies and eligibility for these services appears to also present a significant barrier for families.(18, 19, 22) It is difficult to say who is responsible for providing information to families because everyone involved has a role. In addition, only 15% of parents participating in the situational analysis in Bulgaria reported that anyone helped coordinate their child's care between the different providers.(18)

Smooth support across different sectors for developmental monitoring and early intervention, based on the common principles and conceptual framework.

According to another situational analysis, in cases where not all services are accessible in the same location, parents may spend a lot of time navigating services, limiting time for the child's learning in a natural environment, along with parent-child interactions and parents' employment opportunities. (17) Case coordination may also not be happening when the child and family have to visit many different, discipline-specific services in different places. This fragmentation of services is evidenced by testimonies from survey respondents, which include: "The system is fragmented and largely depends on the family doctor's/paediatrician's willingness for collaboration and coordination", and "ECI services are provided across the health care sector and social welfare sector; however, there is no clear referral pathway, exchange of data, and family-centred service delivery".

Disruptions may also result when the family develops relationships with many different professionals who may potentially give conflicting advice.(17) A lack of inter-sectoral planning has been indicated as an important factor hindering integration and coordination in service delivery.(19, 22) Thus, there remains ample room for improvement in multi-sectoral collaboration and coordination. This consistently appears as a major recommendation for countries where situational analyses have been conducted.

The responses to the survey reveal that pockets of good practice exist and have been reproduced within a project setting. Detailed discussion of this topic is beyond the scope of this publication. The key recommended actions section will provide guidance on key structural elements of interagency coordination and collaboration which is based on literature review.(43)



CASE STUDY

The Early Intervention System in Portugal is the result of the successful implementation and replication of a district-level community-based early childhood intervention programme called the Coimbra Project (started in 1989).(44) At its inception, a coordination team was formed, with one representative from each of the respective regional departments within the health, education and social policy ministries and the National Association of Early Intervention. This team provided organizational support to the project on planning, supervision, training, regular meetings with community teams, project development and implementation, and communication. The positive results of the Coimbra Project and further advocacy led to the approval of Decree 281/2009, laying the foundations of the present Portuguese System of Early Childhood Intervention (SNIPI) and allowing for nationwide implementation.(39)

The current organization of the national ECI system still resembles that of the Coimbra Project. Primary health care facilities have links with early childhood intervention teams which ensure the coordination of all support services for the child and family. All three ministries are part of the national and local ECI system, and teams have professionals 'employed' by different ministries who work together, provide services and coordinate all other services on behalf of the family.(44)



KEY RECOMMENDED ACTIONS FOR HEALTH CARE ON INTRA-SECTORAL AND INTER-SECTORAL COORDINATION AND COLLABORATION

- Accelerate discussions within and between ministries on intra- and inter-sectoral coordination and collaboration related to the early identification of young children who are at risk or have developmental delays or disabilities, and the need to provide support for them and their families.
- Strengthen intra- and inter-sectoral collaboration through: :
 - > Prioritization of the principle of integration in the national strategy and action plans
 - > Building an organizational structure which facilitates coordination and collaboration
 - > Ensuring connection at all levels, through groups of stakeholders working on tasks, and an inter-agency council
 - > Building an integrated inter-agency data system
 - > Building an electronic directory of the resources available in the country
 - > Scaffolding by inter-agency agreements and coordinated policies
 - > Constant programmatic monitoring and evaluation.

3.2 HEALTH WORKFORCE

3.2.1 | PROFESSIONALS INVOLVED IN DEVELOPMENTAL MONITORING



STANDARD OF CARE

Developmental monitoring should be provided by the professional with the best knowledge of and closest contact with the family.

A physician should be available to address health-related risks that that might be present, or provide guidance and supervision on specific situations.

Disruptions in the continuity of developmental monitoring should be avoided at all costs – particularly when the professionals involved are sharing roles.

Developmental monitoring is best when consistently delivered by the same person and at the same location. Primary health care providers are a key human resource for developmental monitoring. (6) There are no clear rules on which professional group should conduct developmental monitoring. Typically, this professional is a physician, nurse or midwife whom the family sees regularly in the community setting. However, the human resources that could potentially be trained to provide developmental monitoring are much broader and may also involve professionals from education or other backgrounds (such as psychologists, social workers, preschool teachers, etc.).

Developmental monitoring should be supervised by a physician whose involvement may be required for the managing of any health-related conditions or to provide guidance on any matters that might arise, for example, when there is no improvement or a referral is needed.

In some high-income countries, such as the United States of America, a paediatrician assumes a major role when delivering services related to addressing developmental difficulties and early childhood development. In other such countries, such as Australia, Canada, Denmark, England, France, Germany, Japan, the Netherlands, Spain and Sweden, different professionals have separate roles.(42) The tasks – such as anticipatory guidance and parental education, identification of developmental difficulties, counselling for targeted issues, referral to intervention and care coordination, and delivery of specialized developmental services – are shared between paediatricians, general physicians and nurses. There is no evidence on which division of roles among medical professionals works best, meaning that ensuring the continuity of developmental monitoring is particularly key in these countries. However, because disruptions in continuity may happen whenever professionals share roles, health care systems should exercise maximum effort to avoid such disruptions happening systematically.

Current state of implementation

The survey (Q10) inquired about 'which professional(s) were conducting developmental monitoring at the primary health care level'. In some countries, this role belonged to a paediatrician or family physician. In others, the responsibilities were shared between professionals (a paediatrician/family physician, nurse/home-visiting nurse, midwife, allied health professionals). The situational analyses from Bulgaria and Serbia captured the fact that there was a consensus among health care professionals on the crucial role of primary health care physicians in conducting developmental monitoring.(17, 18)

The availability of paediatricians/family physicians and home-visiting nurses in primary health care is a strength of the health systems in ECAR. These professionals often have a clinical background conducive to developmental monitoring and can work together or have complementary roles when delivering developmental monitoring.

Disruptions in the continuity of developmental monitoring have happened when a home-visiting nurse was appropriately trained, but the primary health care physician was not. Or if the physician was trained, but the training was conceptually different and incompatible with that of the nurse. Such teams are unlikely to be able to work together cohesively and may even provide conflicting interventions or opposing advice to parents. To avoid such disruptions, professionals should be trained to work as a cohesive team using a common conceptual framework so that 'everyone speaks the same language'. This can be achieved by using the same training package for everyone but adapting the training focus according to their role. Their roles should be clearly defined from the outset and well understood by everyone involved.

The availability of paediatricians/family physicians and home-visiting nurses in primary health care is a strength of the health systems in ECAR.



CASE STUDY

Task-shifting of developmental monitoring to health workers with less training promises to be a feasible approach to expanding the workforce capable of addressing developmental difficulties and early childhood development in countries with low resources. An intervention package for developmental monitoring called the Guide for Monitoring Child Development is currently being implemented in a research context in rural India and Guatemala by community health workers who have secondary school-level education.(45) The Guide for Monitoring Child Development was initially designed for professionals with high levels of education, but such professionals are frequently unavailable in countries with low resources. Subsequently, the Guide for Monitoring Child Development package was adapted for the training of and use by community health workers.(46) The results of this trial will provide valuable insight into the potential for a task-shifting approach to addressing developmental difficulties and early childhood development.

3.2.2 | CURRICULUM FOR DEVELOPMENTAL MONITORING



STANDARD OF CARE

Pre-service and in-service training in knowledge, skills and attitudes for developmental monitoring should be provided to all health care providers engaged in the care of children and their families (such as paediatricians, other doctors, nurses, midwives and allied health care professionals).

All health care providers should be trained using the same conceptual framework to ensure alignment in understanding and support to children and their families.

The training curricula for health care professionals serving children with developmental difficulties and their families should focus on evidence-based diagnostic and therapeutic interventions.

The features of a suitable curriculum in developmental monitoring have been compiled from experience in training health care professionals in ECAR and seminal publications published in the last decade.(6, 9) The training curricula of all professionals involved in developmental monitoring should align with bioecological theory, nurturing care and family-centred, strengths-based care, as well as World Health Organization International Classification of Functioning, Disability and Health.(4, 9, 15, 16, 32).

The importance of training in effective communication skills and establishing partnerships with caregivers cannot be understated.

COMMUNICATION WITH CAREGIVERS SHOULD INVOLVE THE FOLLOWING:

- **Active listening**
- **Trust building**
- **Transparency**
- **Partnership**
- **Praising**
- **A strengths-based approach**
- **The ability to see another person's perspective**
- **Using a non-patronizing communication style which is conducive to partnership, and avoids medical jargon and stigmatizing terminology**

Shaping the attitudes of future health care professionals needs to start as early as possible because otherwise it becomes very difficult to retrain them. Training should include role-play and practical sessions with real children – including those who are developing typically and those with developmental difficulties, alongside their families.

Continuous in-service supervision and mentoring are also necessary to sustain motivation and build capacity in managing specific situations.



THE CURRICULUM SHOULD PROVIDE TRAINEES WITH THE CLINICAL COMPETENCIES REQUIRED TO:

- Build a relationship with the family and apply principles of family-centred care
- Inform the families about the importance of early brain development
- Ask parents about their concerns
- Learn what families are already doing to support child development at home
- Learn about health-related and psychosocial risks, and address common risks
- Use standardized tools to understand child's functioning in domains of expressive and receptive language, gross and fine motor, socioemotional, and self-help skills.
- Learn about the specific strengths and vulnerabilities of children and families
- Share the results of developmental monitoring with the family, establish a rapport, and – together with the family – make a joint plan about what needs to be done at home on a day-to-day basis
- Empower caregivers to provide an adequate and enriched learning environment for their young children
- Know the principles of early intervention and understand the role of other professionals who can help children with developmental difficulties
- Know about the resources in the community and be able to link the family to these resources
- Address stigmatization in their practice, workplace and community

The training curriculum should promote only evidence-based diagnostic and therapeutic methods and interventions.

Non-evidence-based diagnostic assessments and therapeutic interventions are harmful and lack benefits, drain resources from the family and the system, create unrealistic expectations and distort the real problems that need attention. It is important to align national guidelines with evidence-based practices and identify any harmful or non-evidence-based practices and eliminate them. The training curricula of professionals serving children with developmental difficulties and their families should be urgently reviewed and revised accordingly.

The training curricula of professionals serving children with developmental difficulties and their families should be urgently reviewed.

Current state of implementation

Results from the current survey reveal that countries across ECAR have different combinations of pre-service and in-service programmes for doctors, nurses and allied health professionals (Q29). Unfortunately, some countries still have no training programmes for developmental monitoring. Generally, the responses indicate that medical doctors (paediatricians and family doctors) receive some training in all of the developmental monitoring components, and nurses in most of them.

The findings from other recent surveys point to a low level of preparedness of professionals to work with young children and their families.(6, 17-19, 30) In particular, low preparedness has been reported with regard to addressing suspicions that a child may have autism, the use of standardized, validated tools to provide a holistic assessment of a child's development, the assessment of psychosocial risks, and advising parents on how to access early intervention.(6, 17)

Health care providers are generally well aware of health-related developmental risks, gross motor delays, congenital conditions and severe disabilities, which are easily observable. Still, children with conditions that put them at risk, developmental delays, mild developmental disabilities and behavioural problems are often not identified until they are older.(6, 23, 30) Training curricula exist, but they seem to fall short of equipping primary health care providers with the clinical competencies they require to provide developmental monitoring. As a result of deficiencies in training, providers may be afraid of identifying a child with a developmental difficulty.(34) They may feel uncomfortable when making further decisions, such as sharing the results of developmental monitoring, or guiding the family to the services.(34) Deficiencies in the training of primary health care providers are reported to be a major barrier to the implementation of developmental monitoring.(6, 18)

The notion that physical health and development are two inseparable halves of a holistic concept of health has been very slow to translate into the training curricula of health care providers. As a result, the training of primary health care providers has traditionally focused on medical issues. At the same time, everything related to child development has been considered to belong to 'other' specialists working in higher levels of health care or rehabilitation facilities. The existing training curricula are not comprehensive and are commonly confined to a narrow set of skills, such as teaching milestones, red flags, screening tools or checklists.

On the positive side, professionals are aware of the deficiencies in their training and have voiced their desire to receive training on developmental monitoring.(17) Experience in training health care professionals in developmental monitoring suggests that when professionals possess skills and attitudes that they can translate into

their routine practice, this increases their self-esteem and confidence. As a result, the acquired competencies may override the burden of time constraints and the need for health professionals to exert more effort.

Harmful and non-evidence-based diagnostic assessments and therapeutic interventions exist in childcare practices in Europe and Central Asia, and children with developmental difficulties are often subject to such interventions. Some of these practices, prevalent across the countries of the former Soviet Union, were reported in a systematic observational assessment in 2006, before being brought to the attention of a broader audience at a WHO meeting in St. Petersburg in 2007.(47, 48)

One particularly vivid example of such a practice is the misdiagnosis of perinatal encephalopathy, the syndrome of intracranial hypertension in children with mild developmental difficulties or behavioural problems who are otherwise apparently healthy.(49, 50) Other examples include light therapy (the use of ultraviolet light to treat the oropharynx for upper respiratory tract infections), routine referrals of infants for neurosonography (without proper indication) or unnecessary deferrals from immunizations.(48, 49, 51)

There are some pervasive myths about developmental problems (such as 'he will outgrow,' 'she is just a slow learner,' 'his father also talked late,' and many others) which are commonly encountered in the society.(52) Health care providers have an important role in ensuring that appropriate developmental support is not being withheld because of such myths, and should also be careful to avoid perpetuating such myths themselves. Training curricula have an important role in addressing pervasive myths about developmental problems.

The existing training programmes in developmental monitoring reveal additional opportunities for training frontline health care service providers. *In countries where training programmes do not exist, establishing such training programmes is a priority action.*

Harmful and non-evidence-based diagnostic assessments and therapeutic interventions exist in childcare practices in Europe and Central Asia, and children with developmental difficulties are often subject to such interventions.

3.2.3 | SCALING-UP OF DEVELOPMENTAL MONITORING

Successful training will not translate into actual services for families and children if professionals do not have enough time to apply the acquired competencies.

In high-income countries, such as Australia, Israel and the United States, training professionals to address developmental difficulties and ECD involves rotations in developmental-behavioural paediatrics, child psychiatry, or both.(53-55) Trainees in low- and middle-income countries may lack these opportunities.(6) Even if such opportunities become available, the traditional approach of developing human resources through undergraduate or postgraduate training will not yield fast enough results to implement developmental monitoring on a large scale. Fortunately, there is enough regional experience to recommend brief, in-service training to build professionals' capacity in competencies related to developmental monitoring.

Identify and support intrinsically motivated professionals who are willing to champion ECD-related activities. This is one of the most important lessons learned from the experience of introducing and sustaining services related to ECD.(31, 56-58) Scaling up developmental monitoring is not limited to adding new professionals to the pool of trained providers. Other important tasks include advocacy, programme monitoring and evaluation, as well as coordination and collaboration with stakeholders. These 'champions' are intrinsically motivated professionals who take a proactive approach and move the process forward. Regional experience shows that starting by finding the right people significantly increases the chances that efforts will be sustainable. National champions have led efforts to strengthen the local capacity by becoming developmental monitoring trainers, establishing exemplary ECD units, providing consultations to their colleagues on children with suspected developmental difficulties, initiating the collection of monitoring and evaluation data for programmatic purposes, and helping to sustain these services during crises, such as COVID-19.(31, 57, 58)

Address the programmatic aspects of developmental monitoring together with introducing training courses. Introducing training courses without simultaneously addressing the programmatic aspects of what they involve has repeatedly compromised efforts to scale up developmental monitoring. Successful training will not translate into actual services for families and children if professionals do not have enough time to apply the acquired competencies.(21, 31) Instead, they will eventually revert to doing what is convenient.

Another important point to consider is the ownership of efforts to introduce and sustain developmental monitoring. Currently,

UNICEF country offices play a major role in the initiation of discussions about developmental monitoring, while providing technical assistance and logistical support for the dissemination of training. However, it is essential for governments to eventually take ownership of these efforts and allocate the necessary resources, for training and subsequent steps. Resources for training include finances, releasing trainees from their duties for the duration of the course, and ensuring administrative support. Unpublished interview conducted with ECD champion from Kyrgyzstan suggests that little financing for trainings is a significant barrier to scaling-up. (F. Davletalieva, online interview, September 2021) Providing incentives and tackling deterrents to developmental monitoring are other important aspects that need to be addressed.

Align policies with the goal of investing time and resources for children with developmental difficulties. Academics, policy makers and health care providers need to view addressing developmental difficulties and early childhood development as an ethical obligation and investment in the welfare of the nation. This will allow for the prioritization of sustainable scaling-up efforts. For greater detail, refer to Section 3.6 Leadership and governance.

Start by focusing efforts on building capacity in developmental monitoring within one well-defined location. It is very important to pilot training, referrals and supervision locally before replicating them on a wider scale. This will help anticipate and address any barriers that may arise.

Establish training and referral hubs that can serve as centres of excellence and as referral facilities for primary health care. Building capacity at centres that can support training and referrals is vital for sustaining the introduction of developmental monitoring. These centres could also provide clinical supervision and mentoring for primary health care providers. Ideally, the hubs should employ ECD champions, or be established at facilities where these champions are already employed.

The degree of administrative support available at these hubs has a direct impact on how much trained professionals will be able to engage in work related to early childhood development. This is particularly relevant to national trainers, whose additional responsibilities may not be included in their regular job description. Administrative support has been instrumental to sustaining clinical services and in-service training at newly established developmental paediatrics units in large hospitals in Türkiye. (57)

Ensure that all professionals at referral facilities have the same level of knowledge and skills within the same conceptual framework. Previous experience with scaling-up has shown that when professionals at referral facilities are not appropriately trained and do not address the suspected developmental problems in children referred from

Academics, policy makers and health care providers need to view addressing developmental difficulties and early childhood development as an ethical obligation and investment in the welfare of the nation. This will allow for the prioritization of sustainable scaling-up efforts.

primary health care, this may eventually discourage primary health care providers from conducting developmental monitoring and referring children they have identified with developmental difficulties.(21) It is important to avoid training large numbers of primary health care providers before building capacity at referral centres. Capacity building at referral facilities should start ahead of, or concurrently with, the training of primary health care professionals. A large number of referrals could easily overwhelm unprepared referral facilities.

Identify and take advantage of opportunities to introduce training in developmental monitoring within the existing curricula. While there are multiple existing opportunities in every country to introduce training in developmental monitoring, not all of these opportunities will carry the same strategic potential for scale-up. Typically, the introduction of pre-service or in-service training within the existing curricula carries the greatest potential for expanding the workforce trained in developmental monitoring.



CASE STUDY

As a result of the Addressing Developmental Difficulties and Early Childhood Development (ADD-ECD) programme,(31, 57, 58) Azerbaijan has integrated a course on developmental monitoring using the Guide for Monitoring Child Development for paediatricians and paediatric neurologists in the postgraduate training curricula. This was accomplished with the support of the Government of Azerbaijan and UNICEF Azerbaijan through training six national trainers employed at key teaching institutions.

Postgraduate medical education courses related to developmental monitoring are taught at the Department of Paediatrics and the Department of Neurology of the Institute of Advanced Medical Training. This institution is affiliated with the Ministry of Health and it is compulsory for all paediatricians and paediatric neurologists in the country to take the courses offered by these departments once a year. Thus, Azerbaijan is steadily expanding the capacity of its health workforce to deliver services related to developmental monitoring.



KEY RECOMMENDED ACTIONS FOR HEALTH SYSTEMS REGARDING CAPACITY DEVELOPMENT OF THE HEALTH WORKFORCE

WORKFORCE

- Train all health care professionals engaged in providing services for children in developmental monitoring.
- Make sure a trained physician is available to conduct or supervise developmental monitoring.
- Prioritize the delivery of developmental monitoring in primary health care by the same person or team and at the same location.
- When sharing roles regarding developmental monitoring between professionals working in a team, health care systems should exercise maximum effort to avoid systemic lapses in coordination and disruptions in the continuity of care.

CURRICULUM

- Establish training curricula in developmental monitoring that complies with the contemporary conceptualization of early childhood development and developmental difficulties.
- Ensure the training curriculum is experiential and includes exposure to real children with developmental difficulties and their families.
- Ensure the training curriculum promotes only evidence-based diagnostic and therapeutic methods and interventions.

SCALING UP

- Identify and support professionals who are intrinsically motivated and willing to champion ECD-related activities.
- Address the programmatic aspects of developmental monitoring (organization of the service, referral pathways, data collection and reporting, etc.), together with introducing training courses.
- Establish training and referral hubs that can serve as centres of excellence and as referral facilities for primary health care.
- Provide clinical supervision and mentoring to trained professionals in primary care.
- Ensure professionals at all referral facilities have the same level of knowledge and skills, and are trained in the same conceptual framework.
- Identify and take advantage of opportunities to introduce training in developmental monitoring within the existing curricula, particularly with regard to pre-service.



CASE STUDY

The Developmental Paediatrics Unit program was a three-month-long programme that was instituted in 2010 in Türkiye as a model of multilateral cooperation between academia, paediatric referral centres, the Ministry of Health and UNICEF.⁽⁵⁷⁾ The programme aimed to establish and sustain developmental paediatric units in major paediatric referral centres that would provide clinical services, training for paediatric residents, family physicians and allied health professionals, catalyse research and conduct advocacy. Five developmental paediatric units were established in four major cities, and six paediatricians and six child development specialists (allied health professionals from the education sector) were trained. Ankara University's School of Medicine, Department of Paediatrics, Developmental Paediatrics Division provided the training, the Ministry of Health provided the staff salaries and space for the to-be-formed units, and UNICEF funded the travel and accommodation of trainees living outside of Ankara, and equipment for the units.

By 2018, four paediatricians and two child development specialists were still employed at four functioning developmental paediatric units, and the number of children they had been serving had increased over the years. These developmental paediatric units provide clinical services to a large number of children and families, deliver in-service training of paediatric residents, and participate in advocacy activities and research. Today these units are staffed by developmental paediatricians appointed by the Ministry of Health.

3.3 FINANCING OF DEVELOPMENTAL MONITORING

Recognizing developmental monitoring as a part of the basic health care package is an important step. As part of this, it is vital to define the essential content of developmental monitoring and recognize it as a distinct service with an assigned reimbursement code so that the time health care professionals spend working on it can be accounted for and reported. This can be further reinforced by issuing a clear mandate to the particular workforce to perform developmental monitoring, monitor its implementation, and in performance-based health care, preferably, include it among the performance indicators (this will be covered in greater detail in Section 3.4.2, Monitoring and evaluation of the developmental monitoring process). All these steps will help to position developmental monitoring as standard practice within primary health care.

The costs of developmental monitoring should account for staff time in order to ensure full coverage of eligible children, capacity building to increase necessary professional competencies, costs related to data collection and analysis, and the costs associated with procurement of tools for developmental monitoring.

Current state of implementation

Most survey respondents (Q36) stated that the provision of developmental monitoring is already part of the primary health care package. The costs are covered either as part of the preventive health care package or as a separate service within the basic health care package (Q37). The major sources of funding for developmental monitoring across countries are the health insurance fund and the state budget. Non-government sources are also reported to cover the costs in rural areas served by projects.

Developmental monitoring may be recognized as a part of the primary health care package, but in some cases, a range of barriers continue to prevent its implementation. In-depth interviews with a key source from Serbia revealed that “financing covers the total package but, due to the lack of time and many documentation requests at the primary health care level, it would help if developmental monitoring were recognized as a separate service”. This possibly implies that, even if fully financed, developmental monitoring may still not be provided if there are no incentives and the data is not reported. Research is yet to show whether the relevant financing body in each country recognizes developmental monitoring as a distinct service that needs to be delivered as per the guidelines.



STANDARD OF CARE

Developmental monitoring should be made universally available and provided free of charge to children and their families.

The health system should secure financial resources for training in and service delivery of developmental monitoring, ensuring it can be implemented to a good standard by an adequate workforce, and with the required frequency.

Section 3.2.3, Scaling-up of developmental monitoring, has already mentioned that governments should allocate financial resources for scaling-up developmental monitoring activities and take ownership of expenses which are currently covered by UNICEF.

There are many more relevant issues that should be considered under Financing but are outside the scope of this publication.



KEY RECOMMENDED ACTIONS FOR HEALTH SYSTEMS REGARDING FINANCING OF DEVELOPMENTAL MONITORING

- Allocate financial resources for developmental monitoring as an integral part of primary health care provision.
- Define the essential content of developmental monitoring, codify it as a health service and assign a distinct reimbursement code.
- Define the mandate for the delivery of developmental monitoring, monitor its implementation and include it among performance indicators.
- Allocate resources for training staff in developmental monitoring, scaling-up activities, procurement of developmental monitoring tools and integration of this service within existing information systems.

3.4 INFORMATION SYSTEMS AND PROGRAMME EVALUATION

3.4.1 | INFORMATION SYSTEMS

Electronic data collection using health management information systems is very important to support planning, analysis, management and decision making in healthcare.(59) Data on developmental monitoring derived from health care provider-patient interactions in primary health care, facilities or community should also be included in health management information systems. **Data collection at child-level, facility-level, or administrative level (district, regional, national) can inform decision-making and future support for children with developmental difficulties across different sectors.** Data is necessary for planning and informing the allocation of resources within the health system and across other sectors. Data is also a powerful advocacy tool for securing funding for establishing and improving programmes that serve children with difficulties and their families.

Modern technological capabilities, such as digitization and automation, can facilitate all steps from data collection to analysis and, eventually, reporting. When data on developmental monitoring becomes part of the health management information system, it enables the continuity of care, communication with other health departments and inter-sectoral coordination.

Current state of implementation

Data collection capabilities were not evenly balanced across the countries participating in the survey. Data on developmental monitoring was systematically collected in more than half of the surveyed countries, and only a few were collecting data using digital forms (Q33). According to the survey findings, the collected data was only channelled and processed into the relevant health management information systems or special registers in half the countries (Q34). In the surveyed countries where such systems were available, there was systematic reporting on children who had gone through developmental monitoring, children with developmental delays, children with disabilities, children at risk, referrals and the outcome of referrals (Q35). A recent report 'Situation of child and adolescent health in Europe' by WHO found out that less than 25% of Member States collect and report on Sustainable Development Goals indicators related to ECD.(12) Overall, there remains ample space for improvement of systematic data collection on developmental monitoring.



STANDARD OF CARE

Countries should set up mechanisms to enable the systematic collection of child-level, facility-level and administrative-level data on developmental monitoring.

Countries should periodically analyse and evaluate such data to provide inputs into the design of support measures and planning of health and other services.

The data on developmental monitoring should become a part of the child-related health management information system and be linked with other primary health care child-health-related electronic records (e.g., immunization, growth).

The health management information system should facilitate data generation, compilation, analysis, synthesis, reporting and communication.

3.4.2 | MONITORING AND EVALUATION OF THE DEVELOPMENTAL MONITORING PROGRAMME



STANDARD OF CARE

The monitoring and evaluation of the programmatic aspects of developmental monitoring should form an integral part of the activities aimed at its implementation.

These monitoring and evaluation programmes should be designed using participatory approaches to involve health care providers, policy makers, academics, advocates and end beneficiaries (such as children and their families).

Monitoring and evaluation (M&E) represents a set of activities designed to observe how a programme is being implemented, before using this knowledge to make informed decisions on future of the programme, with the aim of its improvement.

The systematic assessment of different programmes carries the potential to explain why a service might have achieved or failed to achieve its desired goals. Such assessments are considered an essential element of the theoretical conceptualization of early intervention systems.(60) As a result, the importance of M&E and of making data-driven decisions cannot be understated, and has been one of the main recommended actions to come from a systematic study of the successful initiatives in the field.(56)

There is no defined set of questions that M&E should answer, and the scope of evaluation depends on what the stakeholders want to know about how developmental monitoring is being implemented. The design of M&E should involve participatory approaches – that is, everyone involved should be able to provide their opinions and share suggestions about what should be evaluated. ‘Everyone’ literally means ‘everyone’, including health care providers, policy makers, academics, families and children. The data collected could be either quantitative or qualitative, or both. The methodological aspects of M&E are beyond the scope of this publication; however, a few examples will be shared below to give an idea.

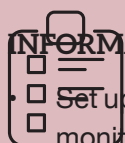
For example, a health care manager may be interested in the rate of developmental difficulties identified at a particular primary health care facility. If they are too low or too high compared to the baseline, the manager may conclude that the health care providers at the facility require more supervision. Meanwhile, health care providers may want to know if their referral rates differ from a neighbouring primary health care facility. Advocates may be interested in knowing whether families think the services are family-friendly and, in turn, families may wish to know whether the primary health care providers typically receive formal feedback from the specialist to whom they were referred. Answering all these questions will yield rich information that is relevant to everyone.

Current state of implementation

The situational analyses of early childhood intervention conducted in Croatia, North Macedonia and Serbia uniformly underscore the need for regular M&E for early intervention in these countries.(17, 19, 22) Although M&E activities are already being conducted in countries where developmental monitoring has been introduced, the data from M&E may only be used for administrative reporting purposes and not for decision making.

When M&E data is not being used for decision-making purposes and is not being fed back into a programme, decisions about the programme are not based on data and remain generic instead. This is likely the result of a lack of understanding of the importance of M&E at all levels. Additionally, because the burden of M&E frequently falls on primary health care providers (on top of their regular tasks), data collection may be suboptimal. Health care administrators may not be aware of the importance of M&E and, for this reason, may not be invested in the process. Health care systems may also not be allocating sufficient resources for M&E (time, staff, mandates). All these factors result in an underappreciation and underutilization of M&E's true potential.

KEY RECOMMENDED ACTIONS FOR HEALTH CARE REGARDING INFORMATION SYSTEMS AND PROGRAMME EVALUATION



INFORMATION SYSTEMS

- Set up mechanisms to enable the systematic collection of relevant data on developmental monitoring, and analyse and provide inputs into the service delivery.
- Make this data a part of child-related health management information systems and link it with other primary health care child health-related electronic records (e.g., immunization, growth).
- Ensure data collection at child-level, facility-level, and administrative level. Make sure this data is used for analysis, synthesis, reporting and communication, and ultimately, informed decision-making.

MONITORING AND EVALUATION

- Conduct monitoring and evaluation activities as an integral part of efforts to introduce developmental monitoring.
- Design monitoring and evaluation activities using participatory approaches to involve health care providers, policy makers, academics, advocates and end-beneficiaries (such as children and their families).
- Allocate resources (financial, staff, mandates, incentives) to monitor and evaluate the developmental monitoring programme.



CASE STUDY

Monitoring and evaluation of a child health programme in Scotland provides a live example of the kinds of data that can be collected and how it can be used to make decisions.(61)

All children in Scotland are offered the opportunity to participate in a child health programme, which includes a series of child health reviews at pre-defined age intervals. These reviews involve asking parents about their child's progress, carefully observing the child and supporting parents in completing a structured questionnaire about the child's development. At the end of the review, health visitors record during home visits whether they have any concerns about each area of the child's development.

All the data is then processed and published, allowing for a better understanding of the key trends in child development at the population level, and can inform policy and programme decision-making. As per the data published on their website: "In 2021/22, there were increases in the proportion of children with a developmental concern at all three review points: 12% of children who received a 13–15 month review, 18% of those at the 27–30 month review, and 15% of those at the 4–5 year review had a concern noted about at least one area of their development". Similarly: "There are persistent inequalities in the proportion of children who are found to have a developmental concern. At 27–30 months, this proportion is 2.3 times higher among children living in the most deprived areas (26%) than those in the least deprived (11%)." Analysis of developmental outcome patterns across different geographical locations has allowed the authorities to conclude that this may be due to differences in practice, indicating the need to work towards greater consistency.

3.5 MEDICAL PRODUCTS, VACCINES AND TECHNOLOGIES

The most important products that health care systems need to procure in order to implement developmental monitoring are standardized and validated tools. This section will highlight a few crucial considerations to bear in mind regarding the selection of tools and their procurement.

3.5.1 | SELECTING STANDARDIZED, VALIDATED TOOLS FOR DEVELOPMENTAL MONITORING

When selecting a developmental monitoring tool, the first thing to consider is its intended purpose. Tools suitable for developmental monitoring should be brief and allow for assessment of a child's development across expressive and receptive language, gross and fine motor, socioemotional and self-help skills. Narrow-band tools that focus on specific domains of development or behaviour do not qualify as suitable for universal developmental monitoring, although they can be used in conjunction with others.

The tool should comply with the principles of developmental monitoring. Tools for developmental monitoring should be used to facilitate communication and interaction between the caregiver and health care provider.(6, 7) The tool should also be conducive to monitoring development longitudinally as the child progressively attains milestones.(7) This means that, for each area of development, the health care provider should be able to use the tool to evaluate what the child is doing now and what should come next for each domain of development, and know whether development is on track or not for this domain of development.

The tool should also facilitate the assessment of the nurturing care environment and developmental risks, and provide guidance to health care provider on planning support and early intervention.

The tool should facilitate the delivery of specific advice based on the child's current stage of development. The tool should help the health care provider to anticipate the child's next progressive milestone and deliver individualized support to the child and family based on this information.



STANDARD OF CARE

Standardized, validated developmental monitoring tools should:

- comply with the principles of developmental monitoring
- possess adequate psychometric properties
- enable the assessment of a child's development across language, relating, play, motor and self-help skills

Standardized, validated developmental monitoring tools should have minimal requirements in terms of documentation, space and equipment

Standardized, validated developmental monitoring tools should be appropriate for programmatic use

Merely administering standardized tools and referring children with abnormal results does not comply with the principles of developmental monitoring.

Merely administering standardized tools and referring children with abnormal results does not comply with the principles of developmental monitoring.

Some of the most widely used standardized and validated tools, such as the Ages and Stages Questionnaire (ASQ), or the Parent's Evaluation of Developmental Status (PEDS).^(62, 63), have been primarily designed as screening tools. Given that screening tools do not provide guidance on the broader process of developmental monitoring, professionals should be taught the skills they need to apply these tools so that they comply with the principles of developmental monitoring. The Guide for Monitoring Child Development (GMCD) has been specifically designed, standardized and validated as a developmental monitoring tool and provides comprehensive guidance on the developmental monitoring process.^(7, 64, 65) but still requires some initial training of professionals for its application.

Psychometric properties constitute an important consideration when choosing standardized, validated tools. The most crucial psychometric property is accuracy (sensitivity and specificity higher than 70% is required). Recent standardization in a sample approximated to the general population or the availability of a nationally standardized or adapted version are other important properties. For example, the GMCD is the only tool with international standardization, while the ASQ and PEDS have standardizations for different populations and require standardization in countries where standardization has not already been done.⁽⁶²⁻⁶⁴⁾ All three have translations or adaptations for diverse cultural contexts across Europe and Central Asia.

Feasibility is another factor when choosing a tool for developmental monitoring, particularly from a programmatic standpoint. Even when a tool has excellent psychometric properties, it might not reach the end beneficiary if training is difficult, takes a long time to administer, or is hard to understand or interpret. Health care providers may eventually stop using tools that do not feel feasible. For example, low literacy in the caregiver may limit the usefulness of written tools that need to be completed by the caregiver.⁽⁶⁾ Low- and middle-income countries may face additional limitations in terms of time, space and funds for the equipment, or it may be difficult to maintain the cleanliness of the space and objects necessary for developmental monitoring. The amount of time spent completing documentation may also present a significant challenge. This is why the requirements in terms of time, space and equipment must be minimal.

Interested readers can refer to a recent scientific review 'Rating Early Child Development Outcome Measurement Tools for Routine Health Programme Use' for factors that need to be considered when assessing existing developmental monitoring and screening tools for their suitability for routine health programme use.⁽⁶⁶⁾

Current state of implementation

A recent report from ECAR has also documented the availability and use of tools with poor or unknown psychometric properties.(27) It is very important that countries abandon the use of tools with unknown or poor psychometric properties.



RECOMMENDED ACTIONS FOR HEALTH SYSTEMS REGARDING THE SELECTION OF STANDARDIZED, VALIDATED TOOLS FOR DEVELOPMENTAL MONITORING

- Implement standardized, validated developmental monitoring tools that provide a brief, comprehensive assessment of development across multiple domains and possess adequate psychometric properties. Avoid the use of tools with poor or unknown psychometric properties.
- Ensure that the standardized, validated developmental monitoring tools being implemented comply with the principles of developmental monitoring and are feasible for use in the given context. Be particularly aware of the shortcomings of written tools in populations with low literacy levels.

3.5.2. | ADOPTION OF TOOLS FOR DEVELOPMENTAL MONITORING



STANDARD OF CARE

Countries should follow best practices when adopting tools for developmental monitoring.

Adopting standardized, validated developmental monitoring tools is the next important step. Below is a summary of the process that leads to the adoption of developmental monitoring tools for use at scale. Not all of these steps will apply to all circumstances; however, they are important to consider.

1. **Agreement and purchasing of the tool.** Any use of a licensed tool other than individual use (for example, institutional use, research or programmatic use) is subject to certain requirements, and there may be associated costs. Typically, the intellectual property rights of standardized and validated tools for developmental monitoring belong either to the tool's developer or a legal entity with whom licensing agreements need to be signed for procurement of the tool. The first step to acquiring the tools is reaching an agreement with the intellectual property rights holder. The agreement may include terms for the use of the tool, such as the location where it will be used, the number of tool administrators, the number of copies per year and the conditions for the tool's proper, intended use.
2. **Formal training.** This is typically the next step that happens concurrently with (or immediately after) the agreed procurement of the tool. The intellectual property rights holder may request that certain conditions be met for the tool's prospective users' formal training before the tool can be used in the relevant country. There may be an additional cost for training provided by the intellectual property rights holder or approved partners. Training national trainers and users is an important process and may take time.
3. **Adaptation of the tool.** Any modifications to the original tool, such as standardization and validation for use in other populations or translation and adaptation into languages other than the original, is subject to permission from the intellectual property rights holder.

The most common modification is direct translation into other languages. The standard translation procedure involves back-translating the translated content into the original language to check for inconsistencies or misinterpretation. This, however, may not be enough, because the tools also need to be culturally adapted for local use. Adaptation may entail rephrasing or using local illustrations, examples, photographs or symbols. It is very important that the national trainers conduct piloting and suggest

further adaptations based on feedback from actual users or beneficiaries of the tool before scaling up.(46)

Even after this has been taken into account, translation and adaptation may prove insufficient and tools may need to be restandardized and revalidated for use in other populations. Restandardization and revalidation is not required for tools with international standardization.

4. **Other requirements.** Besides the actual cost of acquiring the tool, there may be additional associated costs related to the equipment or office supplies required. There may also be costs linked to the space necessary for administering the tool or hygiene precautions, such as cleaning the materials (e.g., toys).

Current state of implementation

The lack of tools and the costs associated with acquiring them was cited as one of the most important barriers to developmental monitoring in the survey, as shown consistently in similar systematic assessments conducted over the past two decades.(6, 17-19)

In-depth interviews with primary sources from Serbia revealed that licensing issues with the intellectual property rights holder of the Ages and Stages Questionnaire came up after the tool had been adapted and validated for use in the Serbian population. This underscores the importance of attending to licensing issues before investing in costly procedures, such as validation.



KEY RECOMMENDED ACTIONS ON THE ADOPTION OF TOOLS FOR DEVELOPMENTAL MONITORING

- Consider the costs associated with procurement, training, modification and adaptation of the tool, and balance the available resources against these costs.
- Follow best practices when adopting tools for developmental monitoring.

3.6 LEADERSHIP AND GOVERNANCE

3.6.1 | POLICY AND LEGAL BASIS FOR DEVELOPMENTAL MONITORING



STANDARD OF CARE

Health care policy should value early childhood development and commit resources (training, time, funds, reimbursement and mandates) for universal developmental monitoring.

A lack of understanding at the policy maker level translates into little or no progress.

Governments should adopt a national policy that values and commits resources to supporting early childhood development. A national ECD policy supports the implementation of programmes and services for young children and their families and serves as an indication that there is a national consensus among the key stakeholders (academics, advocates, clinicians and policy makers) on the key priorities, as well as government commitment to its implementation. Governments with a clear understanding of the importance of developmental monitoring have incorporated this priority into their National ECD Strategy and Action Plan documents. As a result, these governments have succeeded in taking contingent and consequent steps to create the necessary conditions and commit the resources needed for the implementation and expansion of developmental monitoring. On the other hand, a lack of understanding at the policy maker level translates into little or no progress.

The legislation (regulations, orders and decrees) should recognize developmental monitoring as a standard of paediatric care, mandate its routine provision within the basic primary health care package, clarify the duties and responsibilities of the involved professionals, and commit the necessary resources. It should also ensure seamless links to follow-up services for children and their families. National legislation and the terminology used in these documents should be aligned with the social model of disability and the International Classification of Functioning, Disability and Health (ICF).^(32, 38, 41) In particular, policy makers should take measures to eradicate potentially stigmatizing terminology.

Current state of implementation

Several countries in Europe and Central Asia have adopted national ECD strategies and other related policies recognizing developmental monitoring as one of their priorities (e.g., Turkmenistan, Bosnia and Herzegovina, Montenegro and Serbia). The survey (Q6) revealed that the legal basis for developmental monitoring was “recognized as a provision within the basic package of health care”, “recognized

as a priority within a policy document such as a health strategy or an action plan”, “regulated by a specific health care law or by-law” and “a provision as part of the early childhood intervention normative package”.



CASE STUDY

Turkmenistan has been pursuing a contingent ECD policy for the past two decades. Documents such as the National Early Childhood Development Programme for 2011–2015, the Conceptual Framework for Implementation of Developmental Paediatrics and Early Intervention in Turkmenistan: Action Plan 2015–2020, the National Strategy for Maternal, Newborn, Child and Adolescent Health Promotion for 2015–2019 and the National Strategy for Early Childhood Development in Turkmenistan for 2020–2025, are exemplary documents that signify that government policy values ECD and is providing strategic directions for different sectors to support ECD.(67, 68) Building on these policies, the Government of Turkmenistan has made significant progress in introducing universal developmental monitoring and providing early childhood intervention, and is dedicated to scaling up.



KEY RECOMMENDED ACTIONS ON HOW TO IMPROVE POLICY AND LEGISLATION FOR DEVELOPMENTAL MONITORING

- Develop and adapt national policies that support early childhood development with developmental monitoring as one of the key priorities.
- Increase understanding of the importance of universal developmental monitoring at the policy-maker level.
- Align policies to invest time and resources for children with developmental difficulties.
- Engage in collaboration with countries in the region to facilitate exchange and learning across countries, and gain additional momentum.
- Legislate and mandate universal development monitoring as a part of the basic package of PHC services and within other relevant legislation at all levels of administration.
- Align national legislation and terminology with the social model of disability and ICF, and take steps to eradicate potentially stigmatizing terminology.

3.6.2 | NATIONAL GUIDELINES FOR DEVELOPMENTAL MONITORING



STANDARD OF CARE

Establish national guidelines for developmental monitoring that comply with the contemporary conceptualization of early childhood development.

National guidelines are essential to unify approaches and increase fidelity to evidence-based care when addressing developmental difficulties and early childhood development. They describe the overall process and clarify the specific steps. The guidelines need to be comprehensive, have a hands-on orientation and comply with the standards of care outlined in Section 3.1, Service delivery. The guidelines' content should cover the topics listed in Section 3.2.2, Curriculum for developmental monitoring.

The guidelines should facilitate conversations about child development between the health care provider and the family. A recent editorial 'Addressing Early Development in Health Care: Putting Theory into Practice' by leading author in the field Dr Ilgi Ertem outlines the exemplary questions that countries can include in their national guidelines to help health care providers converse about child development.(9)

Should countries wish to include specific milestones from different domains of development for reference, it is important that only clinically meaningful milestones and their respective cut-offs are indicated for each developmental domain.

Support recommendations provided by a health professional to parents should be individualized. This means that they should aim to support the child's current functional level, and facilitate attaining



WHAT ARE CLINICALLY MEANINGFUL MILESTONES?

Clinically meaningful milestones are attained progressively in a sequence by all typically developing children (for example, all children attain sitting independently, but not all children crawl).

They correspond to a functional skill that humans use in their daily life (using a pencil to draw, or drinking from a cup is functional but stacking cubes is not).

Their development can be supported by activities that the caregivers and children can include as part of their daily routine (for example, feeding themselves or drawing).

A clinically meaningful cut-off is a time point after which failure to attain a milestone would indicate a developmental difficulty. For this particular milestone, this would correspond to the 15th percentile, when developmental functioning is below a standard deviation of -1 .

the next functional level for each developmental domain. The advice should not be age-based.

The guidelines should not contain any stigmatizing terminology such as 'mental retardation', 'defect' or 'handicap'. They should avoid using concepts which do not have a scientific basis (such as a child being 'one month behind' other children of the same age).

Current state of implementation

A swift glance at the relevant documents of Azerbaijan,(69) Belarus,(70) and Ukraine,(71) which provide instructions on routine mandated child health care, helps identify potential areas for improvement. The most important shortcoming of the existing guidelines is that they do not go beyond requiring an "assessment of a child's psychomotor development". They also lack a detailed definition of developmental monitoring and do not explicitly state the actions to be taken and advice to be given. The guidelines might not mention learning about the nurturing care available to the child, or prompt to look for and address health-related and psychosocial risks. These gaps should be addressed to further implement developmental monitoring as a standard primary health care provision.

In some countries, the national guidelines on developmental monitoring provide comprehensive guidance for health care providers in using a developmental monitoring tool endorsed for national use. (72) In others, the guidelines might not mention a specific tool and provide general guidance instead. Irrespective of either approach, the guidelines should facilitate conversations about child development between the health care provider and the family. The following case studies share two exemplary guidelines: one that provides guidance based on a tool and the other sharing general guidance and clinically useful milestones.



CASE STUDY

Guidance on developmental monitoring in Turkish child health supervision protocols is an exemplary national guideline, first published in 2003 and recently updated.(72) The guideline supports health care providers in using a nationally endorsed tool for developmental monitoring – the Guide for Monitoring Child Development.

Another recommended reference for guidance on developmental monitoring is the Early Childhood Development section in the Pocketbook of Primary Health Care for Children and Adolescents by the World Health Organization.(36)

Both guidelines comply with the standards of care outlined above, are user-friendly and favour a hands-on approach.

3.6.3 | EFFICIENT MANAGEMENT OF RESOURCES AND OPTIMIZATION OF SERVICE DELIVERY



STANDARD OF CARE

The resources available at the primary health care level are efficiently and effectively managed to support the implementation of developmental monitoring.

Potential for optimization also lies in the sharing of roles between different professionals. Typically, nurses or physicians who see the family regularly are ideally situated to share roles.

Human resources, time and funding remain limited across many different contexts, and their proper management is crucial to creating space for developmental monitoring.

Time constraints are a universal challenge of primary health systems. Researching the workload of primary health care providers may uncover potential areas for optimization. Such an analysis would look into health workers' activities and work processes, their real and perceived routine workloads, and the service delivery's organization. For example, a significant proportion of health professionals' time is spent record keeping or completing arguably redundant activities. Record-keeping could be optimized by introducing an electronic records system, and the captured information could be reviewed to eliminate non-essential or duplicate information.

Further potential for creating space for developmental monitoring lies in optimizing the number of well-child facility-based or home visits for children. To give a sense of the optimal number, the mean number of well-child visits (0–18 years) in Europe is 14.7,(73) and eight visits are recommended for children under 5 in the WHO Pocket Book of Primary Health Care for Children and Adolescents. (36) Countries with a large number of scheduled well-child visits have the greatest potential. For example, in Ukraine, the combined number of home- and facility-based encounters for children under 42 months is cited as 40 in the child health guidelines.(71) Time and resources can be spared if the number of visits is optimized and the content is improved.

Potential for optimization also lies in the sharing of roles between different professionals. Typically, nurses or physicians who see the family regularly are ideally situated to share roles. The most important issue to consider is preventing any unnecessary disruption to the continuum of developmental monitoring, in terms of the professionals performing it and the child and family. Section 3.2.1, Professionals involved in developmental monitoring, addresses this issue in greater detail.

Current state of implementation

The situational analyses of early intervention services in selected ECAR countries consistently report health professionals describing time constraints as a significant barrier to using standardized tools for developmental monitoring.(17, 18) Optimization of service delivery remains an important solution to this wide-ranging issue.



KEY RECOMMENDED ACTIONS CONCERNING OPTIMIZATION OF SERVICE DELIVERY

- Research the workload of health care professionals in primary health care.
- Assess opportunities to optimize the number of planned home- or facility-based visits.
- Consider reviewing the duties of professionals working at the primary health care level to optimize the sharing of roles.
- Consider involving non-medical professionals to support administrative tasks to free up the time of trained health professionals for service delivery.

3.6.4 | INCENTIVES AND DISINCENTIVES FOR DEVELOPMENTAL MONITORING



STANDARD OF CARE

Health systems should incentivize health care providers to facilitate the prioritization of developmental monitoring.

A lack of formal requirements to conduct developmental monitoring and use developmental monitoring tools is one reason why developmental monitoring may not currently be prioritized in primary health care.

The incentivization of health care providers to prioritize essential tasks during service delivery will likely increase the implementation of these tasks. Likewise, the existence of disincentives is likely to result in underperformance. With this in mind, it is important to evaluate service delivery for possible incentives and disincentives. In performance-based health care delivery, tasks for which there is a monetary incentive or reimbursement are prioritized, and potentially compete with other important tasks that are not included in the performance evaluation. Thus, it is important that developmental monitoring is not excluded from the performance indicators if there is a performance-based system in place. The constant prioritization and mandating of developmental monitoring in health care is also likely to serve as an incentive.

A lack of formal requirements to conduct developmental monitoring and use developmental monitoring tools is one reason why developmental monitoring may not currently be prioritized in primary health care.⁽³¹⁾ When not formally required, developmental monitoring invariably receives a lower priority because it takes time, requires action when developmental difficulties are identified, and the results are not immediately visible. Instead, mandated tasks such as vaccination are prioritized, and health care providers revert to a habitual way of working. Thus, health systems need to include developmental monitoring as an integral part of routine child health care, and this needs to be mandated, incentivized and reimbursed. In performance-based health care, a more balanced incentivization scheme should be implemented.

The incentivization of national ECD champions or professionals with additional duties to scale up developmental monitoring (such as coordination, organization, programmatic monitoring and evaluation) is essential for the sustainability of the scaling-up efforts. As explored in Section 3.2.3, Scaling-up of developmental monitoring, this publication recommends incentivizing additional efforts by such professionals – or balancing their regular duties against work related to scaling-up.

Current state of implementation

The available scientific literature and reported experiences of implementation of developmental monitoring in selected ECAR countries suggest that factors such as a lack of training and supervision, time constraints, no reimbursement, no mandate and the absence of services for early intervention may all serve as disincentives to providing developmental monitoring.



KEY RECOMMENDED ACTIONS FOR HEALTH SYSTEMS ON THE INCENTIVIZATION OF DEVELOPMENTAL MONITORING

- Ensure that all the existing disincentives for the under-prioritization of developmental monitoring are eliminated.
- Create incentives for primary health care providers, such as mandating developmental monitoring as an integral component of routine child health care.
- Include reimbursement in performance-based health care, and balance the reimbursement scheme to incentivize developmental monitoring.
- For national ECD champions or professionals who have duties that scale up developmental monitoring, incentivize additional effort, balance regular duties against work related to scaling-up, or both.



ANNEXES REFERENCES



ANNEX 1 | SURVEY

DEVELOPMENTAL MONITORING IN THE PRIMARY HEALTH CARE SYSTEM

SURVEY QUESTIONS

This survey is part of a joint initiative of the WHO Regional Office for Europe and the UNICEF Regional Office for Europe and Central Asia. This survey aims to collect information on how developmental monitoring is organized within the primary health care systems in the European region. The analysis of the existing approaches and models for developmental monitoring will help inform the future work of the WHO and UNICEF, aiming to strengthen support for families with young children aged 0–6 years at risk of developmental delays or disabilities.

COMPLETING THE SURVEY

This survey will take no more than 10 minutes to complete. Most questions have the option to tick multiple answers. Your contribution is very important, and your responses are confidential. Please submit the survey before 1 March 2022, so that the data can be incorporated into the WHO/UNICEF analysis on developmental monitoring.

SURVEY TERMINOLOGY

Screening refers to a brief, one-off assessment of all or specifically targeted children. '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 treatment is available. Examples of screening include genetic testing during pregnancy, vision and hearing tests, and metabolic or hormonal testing during the neonatal period. However, there is a consensus that the word 'screening' is not appropriate for monitoring children's overall development trajectories, as these are complex, and there is wide variation in typical development between children.

Developmental monitoring (DM) aims to track and support every child's development. It differs from screening, which has a predetermined timeframe and seeks to detect aberrations. Developmental screening is implemented as a part of DM, and the survey makes a distinction between 1) neonatal screening and 2) DM as a continuous process within which developmental screening tools are applied at a particular point in time, or as a follow-up to risk identification or concern from a parent, etc. The term DM is used here for approaches in which a health care provider, who follows the child and family regularly, uses instruments to monitor the child's developmental functioning in all areas. Mechanisms used for DM include a clinical interview in which specific milestones are assessed, a brief neurodevelopmental screen using a predetermined list of milestones, or a standardized screening instrument. DM includes the following components:

- Eliciting and attending to parents' concerns
- Maintaining a developmental history
- Making accurate and informed observations of the child
- Identifying risk and protective factors
- Documenting the process and findings

Early Childhood Intervention (ECI) programmes are designed to support young children who are at risk of developmental delay or young children who have been identified as having developmental delays or disabilities. ECI comprises a range of services and supports to ensure and enhance children's personal development and resilience, strengthen family competencies, and promote the social inclusion of families and children.

EXAMPLES OF SPECIALIZED SERVICES INCLUDE:

- Medical
- Rehabilitation (e.g., therapy and assistive devices)
- Family-focused support (e.g., training and counselling)
- Social and psychological services
- Special education, along with service planning and coordination
- Assistance and support to access mainstream services such as preschool and childcare (e.g., referral)

Services can be delivered through various settings including health care clinics, hospitals, early intervention centres, rehabilitation centres, community centres, homes and schools.

Helpdesk

If you require any support while completing a survey or have any questions about the survey, please contact Snezana Ilic at snezilic@gmail.com (in English).

SURVEY

PART 1 | NEONATAL SCREENING

1. **What types of neonatal screening are performed in your country?** *(Please mark all that apply)*

- Neonatal screening for phenylketonuria
- Neonatal screening for hypothyroidism
- Neonatal screening for hearing loss
- Vision screening

2. **Please provide the coverage estimates (%) for neonatal screenings**

- Neonatal screening for phenylketonuria: _____
- Neonatal screening for hypothyroidism: _____
- Neonatal screening for hearing loss: _____
- Vision screening: _____

Part 2 | DEVELOPMENTAL MONITORING

3. **Is developmental monitoring part of the standard practice within primary health care?**

- Yes
- No

4. **If yes, which age groups are covered:**

- 0–2 years
- 3–5 years
- Other: _____

5. **Are there defined age periods when DM is applied?**

- Yes – please specify at what ages _____
- No

6. **What is the legal basis for the provision of developmental monitoring?** *(Please mark all that apply)*

- There is no legal basis for DM
- DM is regulated by a specific health care law or by-law
- DM is recognized as a priority within a policy document, such as a health strategy or an action plan
- DM is recognized as a provision within the basic package of health care
- Other (please specify) _____

7. In terms of its integration into routine health care services, DM is conducted: *(Please mark all that apply)*

- As a part of facility-based well-child visits
- Within distinct facility-based check-up visits scheduled only for DM
- During check-ups linked with immunization services
- During home visits
- During sick-child check-ups
- Within ECD or other counselling services at the PHC level
- Only on higher referral levels (secondary or tertiary health care) following referral from PHC

8. DM findings are based on: *(Please mark all that apply)*

- Clinical assessment (neurology test, reflex examination...)
- Observation (observation during the visit, parent-child interaction...)
- Validated international instruments (developmental screening instruments)
- Nationally-constructed, validated instruments (please provide name: _____)
- The list of developmental risks on which the DM is performed
- Other: _____

9. If health care providers use validated instruments (developmental screening instruments) to detect developmental delay, please select if any of the below tools are used: *(Please mark all that apply)*

- Ages and Stages Questionnaire (ASQ) 1
- Parents' Evaluation of Developmental Status (PEDS) 1
- Guide for Monitoring Child Development (GMCD) 2
- Malawi Developmental Assessment Tool (MDAT) 2
- Rapid Neurodevelopment Assessment (RNDA) 0–2 Years and 2–5 Years 3
- Denver-II Developmental Screening Test (DDST II) 3
- Bayley Scales of Infant Development (BSID-III) 4
- Other (please specify): _____

10. Who is conducting developmental monitoring at the primary health care level? *(Please mark all that apply)*

- Paediatrician
- General practitioners/family doctor
- Nurse
- Midwife
- Home-visiting nurse
- Psychologist
- Special educator
- Other (please specify): _____

11. What are the barriers to using standardized development screening tools in your country?*(Please mark all that apply)*

- Lack of time by health staff
- Lack of trained staff
- Lack of valid and standardized tools
- Associated costs of licensed tools
- Limited funding
- Lack of formal legal requirement
- Lack of guidance at the country level (in terms of who conducts it and how)
- Other (please specify): _____

12. If developmental screening is universal, at which age(s) is it implemented?

Age(s) _____ years

13. What aspects are assessed as a part of DM *(Please mark all that apply):*

- Environmental socioeconomic risk factors
- Biological risk factors
- Family strengths and weaknesses
- Developmental milestones across different domains
- Other (please specify): _____

14. If risks, delays or disabilities are detected, is a follow-up procedure in place?

- Yes
- No

15. If yes, what are the next steps? *(Select all that apply)*

- Interview with parents/caregivers
- Re-evaluation after a defined period
- Family counselling
- Referral to ECI services
- Home visit
- Other (please specify): _____

16. When a developmental delay is identified, is the child referred for an in-depth assessment?

- Yes
- No

If yes, what type of in-depth assessment of developmental delay is available in your country?

- Fragmented – the child is evaluated by different experts who provide multiple assessment reports
- Integrated functional assessment (one / two or more professionals provide assessments to produce one report based on all developmental domains)

17. Who conducts in-depth assessments?

- Specialists from the higher levels of the health system
- Specialists at the primary health care level
- Developmental counselling unit staff
- Experts from other systems such as education
- Multidisciplinary team – Please specify who is involved: _____
- Other (please specify): _____

Part 3 | REFERRAL

18. How long do parents usually wait for an appointment for an in-depth assessment?

- There is no waiting period
- A few weeks
- 1–3 months
- More than three months
- Do not know

19. Once a disability is identified, which type of service is the child referred to?

- In-depth assessment
- ECI services
- Rehabilitation (Rehab Institution/Tertiary Health care)
- Other (please specify): _____

20. Is there a referral to primary health care (PHC) services for DM? (Please mark all that apply)

- Prenatal services to PHC *prenatal risks, genetic risks
- Perinatal service to PHC *prematurity, birth complications
- Education system to PHC *from nursery, kindergarten, preschool (professionals concerns)
- Social welfare system *environmental risks, abuse and neglect, extreme poverty
- There is no referral to PHC services

21. If a professional in PHC suspects that a child is at risk of a developmental delay, whom does he/she inform? (Please mark all that apply)

- Parents
- Expert associates/health care associates (psychologists, pedagogues, special educators)
- Paediatrician
- Health professional at the secondary/tertiary level of the health system
- Preschool, if the child is enrolled
- Social worker if the family is using social services
- Someone else (please specify): _____

22. Are there eligibility criteria for referral to support services or ECI?

- Yes
- No

23. How does the PHC provider ensure follow-up upon referral to services/ECI? (Please mark all that apply)

- Contacts the family to check
- Requests a written report from the professional the child has been referred to
- Speaks to the professionals from the institution/organization to which the child has been referred
- PHC provider does not have the means to check if the family has followed the instructions
- Other (please specify): _____

24. Do the components across the health sector communicate well to maintain efficient and timely DM services and referrals?

- Yes
- No
- Comment: _____

If yes, please specify the components across the health sector: _____

25. Is multi-sectoral collaboration and coordination regarding DM strong and efficient in your country?

- Yes
- No
- Comment: _____

Who is involved in the multi-sectoral collaboration?: _____

Part 4 | QUALITY OF SERVICE DELIVERY (SD)**26. How accessible are the primary health care centres in your country for families? (Select one)**

- Within walking distance
- Accessible by transportation that is affordable to most of the population in every municipality
- Not accessible by transportation that is affordable to most of the population in your municipality
- Other (please describe): _____

27. The primary health care provider conducting DM (please specify) _____ (paediatrician, family doctor, home-visiting nurse...) is trained to (please tick all appropriate):

- Identify biological developmental risk factors (such as low birth weight)
- Identify socioeconomic and environmental factors (such as poverty or family violence)
- Use interview and observational skills to assess aspects of a young child's development
- Use standardized, validated screening instruments to assess the development of young children
- Identify developmental delays in young children
- Identify socioemotional difficulties in young children
- Identify cognitive difficulties in young children
- Identify communication difficulties in young children
- Identify fine and gross motor difficulties in young children
- Use standardized methods to assess malnutrition in young children
- Assess hearing impairment in the first six months of life
- Assess vision in the first six months of life
- Identify children at risk of autism within the first three years of life
- Assess children at risk of cerebral palsy within the first year of life
- Identify suspected child abuse and neglect
- Advise caregivers about how to enhance their child's development
- Advise caregivers about how to access early childhood intervention and rehabilitation services and resources
- Manage the specific health care needs of children with developmental difficulties

28. Do PHC providers consider parental concerns and perspectives in the DM process:

- Yes
- No
- At some point (please specify): _____

29. What types of training programmes for DM are available in your country?

- Pre-service (in schools, before graduation/starting work) training programmes exist: (1) for doctors, (2) for nurses, (3) other, please specify: _____ (select appropriate)
- In-service (during work) training programmes exist: (1) for doctors, (2) for nurses, (3) other, please specify: _____ (select appropriate)
- Both pre-service and in-service training programmes exist
- There are no training programmes
- Other (please specify): _____

30. What is the percentage of the health workforce trained to provide DM screening and counselling?

31. Has any other sector (other than health care) been included in DM and its services?

Please provide details on which aspects of DM are covered by an/other sector(s): _____

32. Please describe three priority actions from your perspective that would improve DM services for children with developmental delays and disabilities.

Part 5 | INFORMATION SYSTEM (IS)**33. Is data from DM systematically collected?**

- Yes, through paper forms
- Yes, through digital forms
- No
- Other (please specify): _____

34. Is the collected health care data on DM channelled into a Health Management Information System (HMIS) or a special register and processed? (Please mark all that apply)

- Yes, to a digital HMIS
- Yes, as a part of a paper-based system of administrative data
- Yes, into a special register (specify which): _____
- There is no HMIS
- No

35. If your country has an HMIS, which indicators are systematically reported: *(Please mark all that apply)*

- Children who went through DM
- Children at risk
- Children with developmental delays
- Children with disabilities
- Referrals
- Outcome of referrals

Part 6 | FINANCING

36. Is provision of DM funded as a part of the PHC package?

- Yes
- No

37. How are the costs of DM covered?

- As part of a preventive health care package for children
- As a separate service within a basic health care package
- As a separate service not covered by insurance
- Other (please specify): _____

38. What is the primary funding source for developmental screening and developmental monitoring in your country?

- Government (national/local), through the state budget
- Health insurance fund
- Private health insurance
- Non-profit organizations (NGOs)
- Other (please describe): _____

39. Is it necessary to obtain fees from parents or donor support to help cover the cost of DM services at the primary health care level in your country?

- Yes
- No
- Do not know

ANNEX 2 | A MODEL FOR THE PREVENTION OF DEVELOPMENTAL DIFFICULTIES

	Preconception	Prenatal/perinatal	Newborn	First years of life
CLINICAL CARE		Emergency obstetric care and immediate emergency care for newborn babies Skilled obstetric care at birth and essential care for neonates (hygiene, warmth, breastfeeding)	Appropriate tertiary care for high-risk newborn Extra care of low birth weight newborns, including kangaroo mother care	Emergency care and intensive care Management of childhood illnesses and disorders;
OUTPATIENT AND OUTREACH SERVICES	Folic acid and iron supplementation Family planning Genetic screening and counselling	Referral of high-risk pregnancies to tertiary centres Antenatal corticosteroids Termination of pregnancy for detected abnormalities Tetanus immunization Prevention of prenatal infections Prenatal screening Pregnancy follow-up Elected abortion of unintended pregnancies	Extra visits for low birth weight newborns Early recognition and treatment of neonatal jaundice and infections Early detection and referral of neonatal complications Newborn screening	Community-based rehabilitation Early intervention for children with developmental difficulties Early detection and management of developmental difficulties Early intervention for children at risk of developmental difficulties Early detection and treatment of iron deficiency Parenting education for high risk groups (e.g. adolescents) Developmental and behavioural monitoring and support Prophylactic iron supplements Promotion of caregiver knowledge and skills to provide nurturing and stimulating environment for young children Health supervision visits Home visiting Vaccinations Nutritional counselling and growth monitoring
			INTEGRATED MANAGEMENT OF CHILDHOOD ILLNESSES	
			EARLY DETECTION AND TREATMENT OF MATERNAL DEPRESSION	
FAMILY AND COMMUNITY	Prevention of adolescent pregnancy Reproductive health Adolescent health Education of girls	Recognition of danger signs, emergency preparedness Counselling and preparation for newborn care Preparation for parenthood Reduction of workload	Promotion of mother-newborn and family bonding Prevention of neonatal infections Exclusive breastfeeding	Prevention of violence, abuse and neglect Early recognition and caregiver management of diarrhoea with oral rehydration salts Salt iodination Promotion of parenting competence for optimal development
	PROMOTION OF CHILD, FAMILY AND COMMUNITY RESILIENCE →			
	PROMOTION OF MATERNAL, PHYSICAL AND MENTAL HEALTH →			
	IMPROVEMENT OF SOCIAL DETERMINANTS OF HEALTH - healthy nutrition, safe housing, environmental hygiene, living-wage jobs, gender equality, appropriate child care, preschool opportunities and schools, access to public and private goods and services, access to health care and appropriately trained health care providers.			

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