THEMATIC BRIEF

NURTURING CARE
FOR EARLY CHILDHOOD DEVELOPMENT

Nurturing care for children with developmental delays and disabilities

Rahim, 3, with a language delay, plays with a health worker in Pakistan.
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All children, including children with developmental delays and disabilities, need nurturing care.

Nurturing care can protect children who are exposed to risk factors for sub-optimal development as well as improve functioning and long-term outcomes of children with developmental delays and disabilities.

Unfortunately, multiple reasons including poverty, discrimination, limited access to services, and insufficient support to their caregivers result in these children being deprived of nurturing care. This deprivation limits their ability to develop their capabilities and effectively participate in society.

The United Nations Convention on the Rights of the Child *(1)* and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) *(2)* commit governments to creating enabling environments for all children, in particular children with developmental delays and disabilities, to receive nurturing care. However, these children and their families are often left behind in policies and services by their nations and communities. Whole-of-government and whole-of-society approaches are needed to ensure caregivers have the knowledge, support and resources they need so they can, in turn, provide their children nurturing care.

What is nurturing care?

What happens during early childhood (pregnancy to age 8) lays the foundation for a lifetime. We have made great strides in improving child survival, but we also need to create the conditions to help children thrive as they grow and develop. This requires providing children with nurturing care, especially in the earliest years (pregnancy to age 3).

Nurturing care comprises five interrelated and indivisible components: good health, adequate nutrition, safety and security, responsive caregiving and opportunities for early learning. Nurturing care protects children from the worst effects of adversity and produces lifelong and intergenerational benefits for health, productivity and social cohesion.

Nurturing care happens when we maximize every interaction with a child. Every moment, small or large, structured or unstructured, is an opportunity to ensure children are healthy, receive nutritious food, are safe and learning about themselves, others and their world. What we do matters, but how we do it matters more.

This *Thematic Brief* outlines how nurturing care is relevant for children with developmental delays and disabilities. Recommended for policy-makers and programme designers, this Brief recognizes that these children have diverse needs requiring different levels of coordinated and family-centred support aligned with the individual needs of these children and their families. Most relevant for children up to 5 years of age, it recommends a set of actions to strengthen policies, services, communities and caregiver capabilities so that these children receive nurturing care.

Who are children with developmental delays and disabilities?

Children with developmental delays and disabilities are a highly diverse population group. It includes children born with a condition that affects their physical, cognitive or psychosocial development. It also includes children who acquire a condition and/or impairment after birth. Some children are at risk of a developmental delays because of chronic health or genetic conditions, exposure to birth asphyxia, low birth weight, prematurity, malnutrition including micronutrient deficiencies, poor maternal health, prenatal and postnatal infections neurotoxic exposure (i.e. lead, mercury), exposure to poverty and violence and poor caregiver-child interactions among others *(3)*.

Children with a developmental delay refers to those who experience significant variation in the achievement of expected milestones for their actual or adjusted age *(4)*. Children with a developmental disability refers to those with "health conditions that affect the developing nervous system and cause impairments in motor, cognitive, language, behaviour and/or sensory functioning. In interaction with various barriers and contextual factors, these impairments may hinder a child's full and effective participation in society on an equal basis with others" *(3)*.

Children with developmental delays and disabilities are not a homogenous group, and the barriers they experience may differ not only based on their impairment but also on characteristics such as gender, socioeconomic status, ethnicity, geographic location and religion. The causes and nature of disabilities vary widely, as do the severity of the limitations experienced. Environmental modifications, policies, social support and early childhood interventions (ECI) and therapies, as well as nurturing care, may improve the child's functioning and long-term outcomes, and benefit families and communities.

Terms are used differently across cultures and within stakeholder groups. This *Brief* uses person-first language and terms consistent with the UNCRPD *(2)*, the Global report on children with developmental disabilities *(3)* and WHO's Global report on health equity for persons with disability *(5)*.

This language aligns with WHO's International Classification of Functioning, Disability and Health which clarifies that disability is not a health condition, but rather results from the interaction of a person's impairments with various societal, physical or environmental barriers *(6)*.

Shafi, who has physical and mental impairment, laughs while interacting with a caregiver in Bangladesh.
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Components of nurturing care

GOOD HEALTH

Refers to the health and well-being of the children and their caregivers. Why both? We know that the physical and mental health of caregivers can affect their ability to care for the child.

ADEQUATE NUTRITION

Refers to maternal and child nutrition. Why both? We know that the nutritional status of the mother during pregnancy affects her health and well-being and that of her unborn child. After birth, the mother's nutritional status affects her ability to breastfeed and provide adequate care.

SAFETY AND SECURITY

Refers to safe and secure environments for children and their families. Includes physical dangers, emotional stress, environmental risks (such as pollution), and access to food and water.

OPPORTUNITIES FOR EARLY LEARNING

Refers to any opportunity for the infant or child to interact with a person, place, or object in their environment. Recognizes that every interaction (positive or negative, or absence of an interaction) is contributing to the child's brain development and laying the foundation for later learning.

RESPONSIVE CAREGIVING

Refers to the ability of the caregiver to notice, understand, and respond to their child's signals in a timely and appropriate manner. Considered the foundational component because responsive caregivers are better able to support the other four components.

Facts and figures *(7)*

Increased risks of children with disabilities compared to other children

Good health

More likely to miss out on vaccinations or access services.

More likely to have childhood illnesses, for example, 1.5 times more likely to have symptoms of acute respiratory infection and 1.7 times more likely to have diarrhoea.

Adequate nutrition

More likely to be undernourished, for example 34% more likely to be stunted and 25% more likely to be wasted.

Represent a disproportionate share of children in institutions and are less likely to benefit from nutritional programmes, which are often not extended to institutions.

In humanitarian situations, are at risk of malnutrition because their particular needs are not usually taken into account.

Safety and security

32% more likely to experience severe physical punishment at home.

10 percentage point lower rate of birth registration, placing them at higher risk of human rights violations and inadequate access to services.

Less likely to have improved sanitation facilities in their households essential to ensure food safety and infections protection, for example 12% less likely to have improved drinking water sources and 8% less likely to have water and soap for handwashing.

Less likely to engage in activities with their caregivers that promote their development, for example 16% less likely to read or be read to at home.

Opportunities for early learning

Less likely to attend early childhood education, for example only one in five children with a disability attends.

Responsive caregiving

25% less likely to receive early stimulation and responsive care.

Rameen, 2, who has Down syndrome, plays during rehab in Pakistan.
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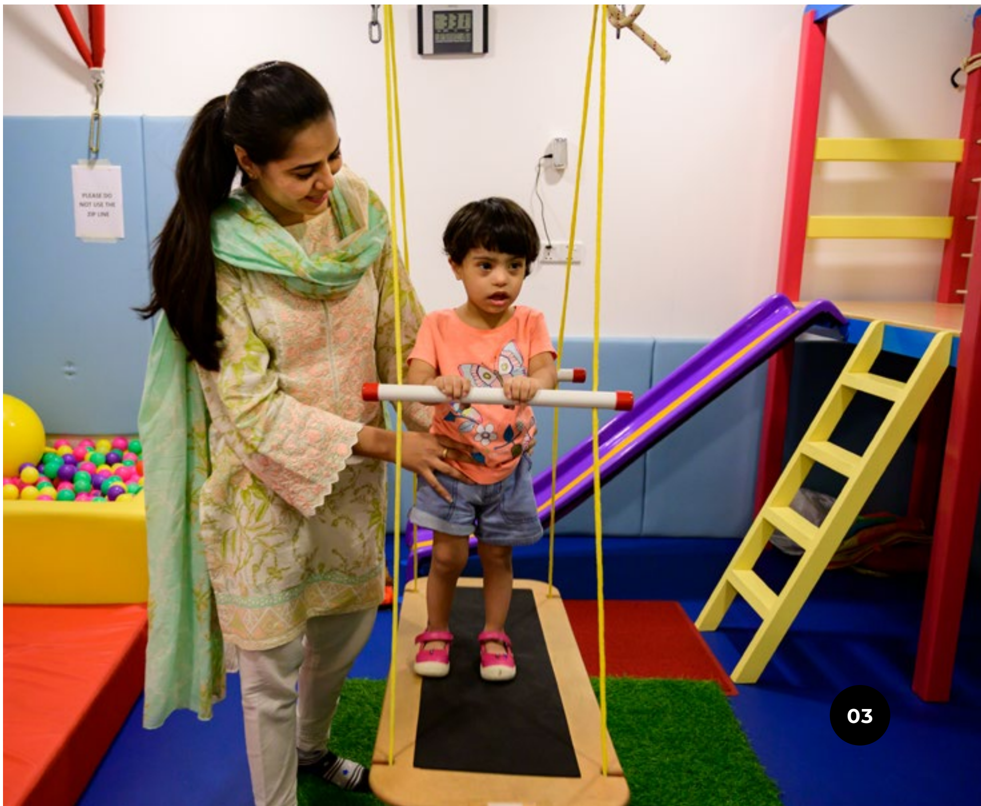

How are children with developmental delays and disabilities missing out on nurturing care?

Despite gains in childhood survival, more effort is needed to improve the well-being of children with developmental delays and disabilities, especially in countries with overburdened and fragile health care systems *(8)*. Nurturing care can contribute to preventing developmental delays and protect children who are exposed to risk factors, as well as improve functioning and long-term outcomes for children with developmental disabilities. However, attitudinal, physical or systemic barriers experienced by these children and their families result in missed opportunities for nurturing care. Attitudinal barriers include stigma and discrimination owing in part to limited awareness. Physical barriers are related to poor access to basic rights such as health facilities, schooling, and community spaces. Systemic barriers include absence of inclusive policies, legal frameworks, costed strategic plans, services, trained personnel, economic and social exclusion and institutionalization. Any of these barriers may deprive children from receiving nurturing care (see Facts and figures).

Caregiver well-being and mental health

Caregivers are often experts on their child's development and are best placed to provide their children nurturing care, but they cannot do it alone. They need a network of support – peers, community, services, insurance, policies – that address barriers, alleviate stress, and enable them to care for themselves and their children.

Caregivers of children with developmental delays and disabilities may encounter numerous challenges including stigma, lack of support from family and community, inadequate or inaccessible information about or limited availability of resources (such as medications or treatment), as well as loss of livelihood (e.g. reducing work hours to care for children). They may neglect their own health and well-being, or lose their social support network. Caregivers may struggle to care for their children while also tending to other household responsibilities. These caregivers are vulnerable to mental health challenges and stress and may find it difficult to initiate and/or sustain nurturing care practices without adequate resources and support.

A young child supported by her mother climbs a ladder as part of her rehabilitation training in Tajikistan.
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Guiding principles to ensure children with developmental delays and disabilities receive nurturing care

Governments have committed to guarantee and protect children's rights. They are also obliged to ensure caregivers have access to support and services to care for themselves and their children. This includes children at risk of or with developmental delays and disabilities and their families. The guiding principles based upon the UNCRPD and a rights-based approach to disability inclusion, adopted by the whole-of-government and whole-of-society, can ensure all children develop their capabilities and effectively participate in society. The principles highlighted below adopt a biopsychosocial approach which addresses the barriers and creates inclusive environments so as to improve the functioning and health outcomes of every child.

1. Individualized care.

All children at risk of or with developmental delays and disabilities have a right to access services that cater to their unique needs. Understanding, recognizing and tailoring support to each child can ensure that any contributing risk factors are addressed and caregivers are supported to develop skills and confidence to meet the care and developmental needs of their child.

2. Family-centred care.

Caregivers and other intimate family members are the people most consistently present in children's lives and are best placed to provide nurturing care. Service providers who adopt a family-centred approach value the intimate knowledge caregivers have about their children's abilities and needs and treat caregivers as knowledgeable partners. They involve and support other carers proximal to the child (e.g. grandparents, neighbours). They share information about the child and resources, equip caregivers with skills to support their children's specific needs, ask about and address caregivers' concerns, connect caregivers to other services or resources in the community, and guide caregivers to make informed decisions and improve their ability/confidence to provide nurturing care. Service providers treat each family as unique and tailor their support according to its specific needs.

3. Coordinated care.

Children with developmental delays and disabilities and their caregivers often find themselves trying to navigate a multitude of disconnected or contradicting services, messages and policies. Policy-makers, programme planners, implementers and communities should ensure case management, transdisciplinary care and referral systems solutions so that such services efficiently support children and caregivers. Case managers or service providers can help caregivers set goals and support their child during daily activities as well as understand and use recommended services. Such coordinated efforts will help eliminate any potential barriers to use these services. To support case management systems, a unified referral system among different sectors should be a priority.

3 guiding principles

1. Individualized care
2. Family-centred care
3. Coordinated care

At least

43%

of children under 5 are at risk of having a developmental delay, because of inequalities such as extreme poverty, undernutrition and violence *(9)*.

In 2019,

58.9 million

children under 5 years were estimated to have a condition contributing to developmental disabilities, such as hearing loss, idiopathic developmental intellectual disability, attention deficit hyperactivity disorder, cerebral palsy or vision loss *(3)*.

What actions can be taken?

Many countries are already working to ensure that the rights of children at risk of or with developmental delays and disabilities are met through their inclusion in policies and access to services.

This section outlines actions that provide enabling environments for children at risk of or with developmental delays and disabilities and their caregivers, spanning policies, services, communities and caregivers. While all sectors (health, education, social and child protection, among others) need to work together to develop an integrated system of services, this Brief focuses primarily on actions that can be taken by the health sector, in coordination with other sectors. The involvement of individuals and organizations of persons with disabilities and other local actors will help strengthen and amplify the work underway and ensure that the voices of the children and their caregivers are reflected moving forward.

Enabling policies

All too often, the needs of children at risk of or with developmental delays and disabilities and their families are left out of planning and decision-making. This deepens inequities and leaves behind those children who could benefit the most.

Improve policies, laws and national strategies

All relevant policies, laws and national strategies should address the barriers that hinder children at risk of or with developmental delays and disabilities from receiving nurturing care and developing to their full potential. This includes sector-specific policies (e.g. health, nutrition, education, social and child protection, community development), ECI policies, comprehensive early childhood development policies, emergency preparedness and response plans and national strategies on service provision across relevant sectors and different levels of care. Such policies should support equitable access to services, early identification and intervention, and deinstitutionalization, parallel to promoting inclusion and participation and preparing community support, budget allocations and schemes that support caregivers (e.g. insurance, social benefits such as, conditional cash transfers, parental leave, respite care, etc.). (See Rwanda example on deinstitutionalization and Viet Nam example on social benefits).

Work together across sectors and stakeholder groups

Coordination with and between sectors is essential and extends to non-state actors. Sectoral and intersectoral governance mechanisms can create platforms for understanding and addressing the needs of children with development delays and disabilities and their caregivers at national and sub-national levels. These mechanisms should include the voices of individuals and organizations of persons with disabilities as well as partners such as the private sector, civil society, academia and community groups to capture different perspectives and jointly identify solutions. Strengthened coordination and communication can improve policies, budgeting, programming, services, data collection, training and referral pathways, with benefits for all children and caregivers, including those with additional needs. Strengthened collaboration across state and non-state actors can leverage different sources of technical and financial resources.

Collect and use relevant data

The availability and sources of data for estimating the prevalence of children at risk of or with developmental delays and disabilities vary widely by country. Continuing to collect high quality and reliable information will allow for a better understanding of who needs support, what kind and where. This can be complemented by establishing child tracking systems to monitor access to and utilization of services for every child. Information management systems should be able to capture the number of children requiring support and accessing services (disaggregated by age, sex, type of impairment, socioeconomic status) so as to enable exchange of information between sectors, planning and coordination. Additionally, caregiver-reported questionnaires can be used in national surveys to better understand the prevalence of children requiring support, for example the Global scales for early development covering infants from birth to 23 months *(10)*, Child functioning module covering children 24 to 48 months *(11)*, and the Early childhood development index 2030 covering children 24 to 59 months *(12)*.

RWANDA

Community volunteers help children transition from institutions to family care

The term "deinstitutionalization" refers both to the return of children to the community from institutional settings and the prevention of entry to institutions, where children often receive suboptimal nurturing care. This process seeks to prevent the separation of children from their caregivers and supports the reintegration of children into families and communities.

The Government of Rwanda, in collaboration with UNICEF, established the Tubarerere Mu Muryango [Let's Raise Children in Families] (TMM) programme to enable the closure of large-scale institutions and promote family-based care. TMM focuses on establishing a strong childcare system through workforce strengthening and developing support to families and caregivers. It aims to safely reintegrate institutionalized children into families and communities. TMM pays particular attention to children with disabilities and ensures that they are matched with suitable and sustainable care arrangements.

Drawing on Rwandan values of collective responsibility and community support networks, TMM has trained traditional Malaika Mulinzi (Guardian Angels) as volunteers to identify, support and monitor the well-being of children returned to family care. Outcomes of TMM include a significant reduction of children in institutional care and over 29 674 volunteers recruited and trained across the country; and church and community leaders engaged in spreading awareness of the importance of family-based care. The programme has shown how culturally-appropriate services, resources and solutions can be sustainable and used to support integrating children with disabilities into families, thereby contributing to their inclusion in society *(13).*

VIET NAM

Social benefits can enhance support to families

Children with developmental delays and disabilities require care which usually means greater expenses for the family for services, equipment, medication and transport which are often not covered by national health insurance or social protection programmes. Caregivers often need to spend less time working or stop work completely, thereby reducing household income and adding to financial strain. This situation makes it harder for caregivers to care for their children and may have a negative impact on their own health and well-being. This, in turn, can negatively impact their interactions with their children possibly resulting in maltreatment, an inability to provide nutritious food, less time with their children, and a weakened capacity to understand and respond to their children's cues.

Social benefits can help alleviate the financial strain and mitigate negative outcomes for these children and their caregivers, as can income support, such as unconditional cash transfers and vouchers for transport and food. Cash transfer programmes, implemented in over 50 countries worldwide, are an instrumental strategy to enable much-needed support for families *(14).*

In Viet Nam, eligible families are entitled to monthly income support, health insurance, education assistance, travel help, and a support allowance. Caregivers can also apply for a low-interest loan to be used for business development or other job creation activities. Committees at the community or ward level help determine eligibility.

For more information, see *(15).*

Nguyen Hoang Nhan, with autism, learns together with his mother in Viet Nam.
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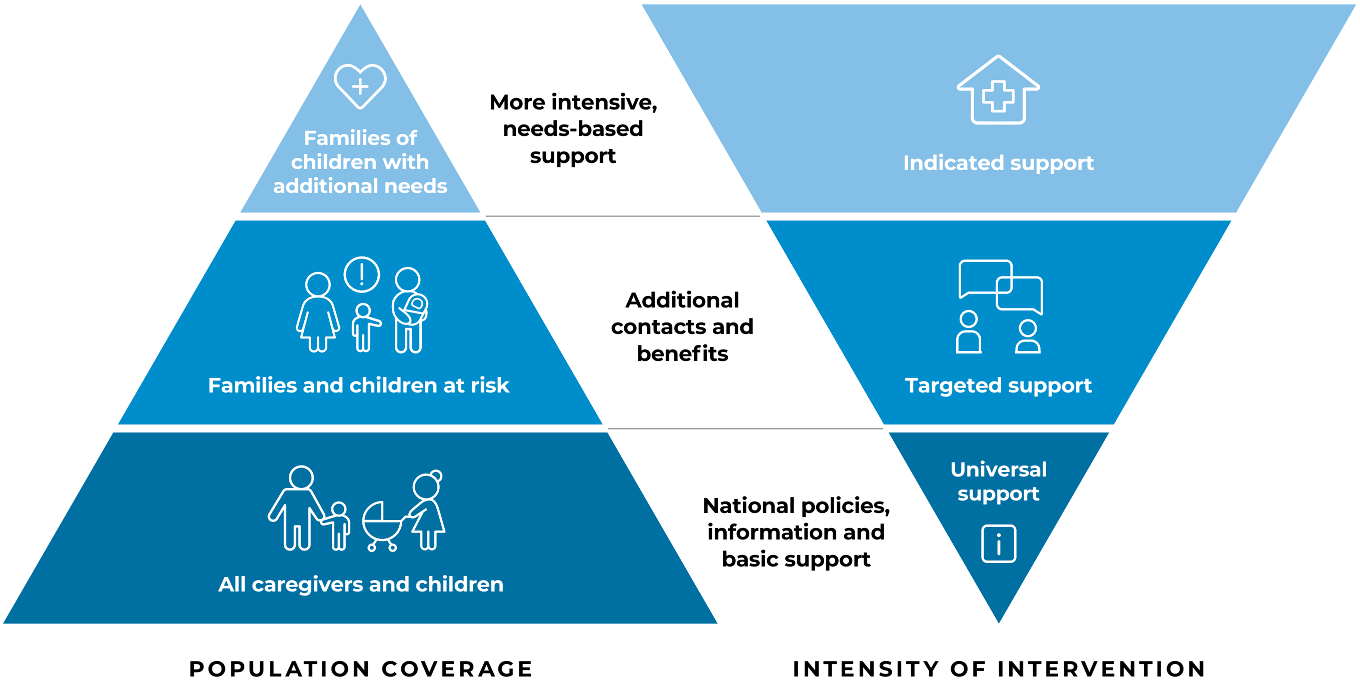
Supportive services

A wide range of health-related and psychosocial factors impact children's developmental trajectories and can increase risks for developmental delays and disabilities. Prevention, promotion, early identification, and interventions tailored to needs can ensure that all children receive nurturing care and achieve optimal development. Services should be culturally and linguistically appropriate and offered in a confidential and ethical manner.

Make available multiple pathways for support

The specific, evolving needs of children at risk of or with developmental delays and disabilities may require them and their caregivers to utilize multiple services at different levels of care (primary, secondary, tertiary) and varying levels of support at any given time (see Figure 1). Services intended for all caregivers and children (universal) can mitigate potential problems by promoting optimal health and development (e.g. counselling on appropriate activities) and identifying and supporting children who are at risk of or with developmental delays and disabilities. Depending on the nature of the delay or developmental disability, additional services (targeted or indicated) tailored to the individual may be needed. This aligns with the twin-track approach which proposes mainstream services (universal) for all children and targeted (targeted or indicated) services for those requiring additional support. These services span health, development, education and social care thereby creating multiple pathways to provide support. An effective system establishes a unified inter-sectoral and inter-institutional referral and follow-up system among all participating sectors.

Figure 1. Meeting the needs of all children, including those at risk of or with developmental delays and disabilities



By adopting a "nurturing care lens", services across the three levels of support can reinforce existing supportive caregiver practices across all components of nurturing care, support caregivers to develop new ones, and equip caregivers with the knowledge and resources to care for themselves and their children *(16)*.

Ensure universal services are inclusive and accessible to all children and caregivers

Inclusivity and accessibility require addressing the knowledge and skills of service providers as well as the attitudinal, physical, systemic and other barriers that hinder the utilization of services. Important actions include: monitor current access and coverage to determine what proportion of children require targeted or indicated services and what proportion are accessing them; address barriers to services such as the attitudes of managers and front-line workers; create referral systems and new services, such as ECI and rehabilitation, including at community level; and fill gaps in the workforce by upgrading skills and growing a pool of specialists.

Establish ECI services

Children at risk of or with developmental delays and disabilities should benefit from timely access to the appropriate intensity of support (e.g. early identification and intervention, early education, a welcoming and inclusive community). Their caregivers should receive timely psychosocial support including financial assistance and peer support. Providing this kind of support early can be cost-effective by preventing negative outcomes, reduce requirements for intensive care and rehabilitation across the life course *(17)*, and *enhance the skills and confidence of caregivers to provide their children nurturing care*. (See box on ECI services).

ECI services

ECI services are designed for families with young children (beginning at birth) who are at risk of or have developmental delays and disabilities. These services help to identify these children as early as possible, provide timely support and redirect positively the course of the child's development. They include a range of individualized services to improve child development, participation and resilience through strengthening the competencies and capabilities of caregivers to responsively attend to the physical and developmental needs of their children. ECI services can be delivered in a range of settings including health facilities, rehabilitation centres, community centres and preschools. However, they work best when they are family-centred, strengths-based, home-based grounded in daily routines and the planning of delivery of services is done together with caregivers, ensuring participation of the family at every stage.

To enhance access and quality, ECI services should be multisectoral, integrated and transdisciplinary, with clear coordination and referral pathways. Multiple individuals may be involved in implementing the services including health specialists such as occupational therapists, paediatricians and neurologists and others such as social workers, teachers and caregivers. Task-sharing and competency-based training can enable all involved, including the families themselves, to play complementary roles in a team aligned with the individual needs of the child and family.

Disha ("direction"): The Indian Ministry of Social Justice and Empowerment has established a national scheme, called "Disha," supporting states to establish centres for early identification and intervention offering therapy, training and family support.

See *(18)* to learn more about the experiences of setting up ECI services in Croatia and Serbia.

Abdukholik, 3, with delayed psycho-verbal development, improves his speech and becomes more sociable in Tajikistan.
© UNICEF/UN0627792/Ruziev

Iron, folate and iodine deficiencies in pregnant women can lead to small-for-gestational-age babies, neural tube defects, and cognitive and behavioural impairments in children. In childhood, vitamin A deficiency can cause blindness, vitamin B deficiencies can cause neurological impairments, and iron and iodine deficiency are the most common causes of intellectual disability *(19)*.

Address risk factors for child development

Among the wide range of risk factors affecting child development, many can be mitigated. These include maternal malnutrition before and during pregnancy, prematurity and low birth weight, birth asphyxia, and nutritional deficiencies in young children. To mitigate these risks, quality of care and effective coverage of essential interventions is critical, starting before pregnancy and sustained throughout childhood. Now that technological advances allow more small and sick newborns to survive, the availability of infant- and family-centred developmental care, starting from birth, is critical to improve health and development outcomes. Regular monitoring of children's growth and development, as well as of the health and well-being of their caregivers, is an entry point for counselling and delivery of interventions.

Screen newborns

Several congenital conditions, including metabolic conditions and sensory impairments, can result in disability if undetected. Careful newborn examination and prompt screening should be administered to detect conditions such as vision and hearing impairment, hypothyroidism, phenylketonuria, as well as infectious diseases such as HIV.

Integrate developmental monitoring into routine services

Service providers should conduct developmental monitoring as part of routine (e.g. well-child) services. In several countries, home-based records (e.g. child health booklets) include a set of milestones as an entry point. However, monitoring goes beyond simply assessing milestones. Regular developmental monitoring provides important information about the child and the home environment to inform subsequent care. When needed this can be complemented with further screening, diagnostic and functional assessment. (See box on developmental monitoring for an explanation and the India example on Equipping health care providers to monitor children's development).

Developmental monitoring

Developmental monitoring aims to keep track of, and support, each child's development. It differs from screening, which has a predetermined timeframe, 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 the way 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 also educates providers about the rights of children with developmental difficulties, as well as how to support families using interventions, including community-based resources. Approaches for monitoring children's individual development are recommended as part of the *Nurturing care framework*. They are characterized by informed watching, enjoying, and supporting the child's development, with the family. They also include partnering with caregivers to enhance strengths, address risk factors, and provide additional individualized support and services when needed *(20)*.

Enhance access to and use of assistive technologies (ATs)

Comprising products and related services, ATs improve the functioning of children with disabilities and contribute to their effective participation in society. ATs may include simple devices such as walking sticks, and more technical ones, such as hearing aids. Although the UNCRPD urges governments to ensure affordable ATs and related services, the lack of trained professionals, costs, and availability of products are among the many barriers to provision *(21)*. National policies and budgets should include procurement, maintenance and support for the use of ATs. Service providers should be trained to identify appropriate ATs and continuously support children and their caregivers to use them. (See example on ATs in South-east Europe).

Create transdisciplinary teams around the child

Services and human resources may need reorganizing to enable service provider teams to support children at risk of or with developmental delays and disabilities and their caregivers, including the establishment of protocols for coordination, consultation, and referral. These teams can work jointly with caregivers to establish individualized plans aligned to needs and preferences. A care coordinator can help caregivers navigate services, inform caregivers of their child's rights, and provide guidance on available support (e.g. financial aid). Training should be interactive and include reflections on team members' biases and assumptions about children at risk of or with developmental delays and disabilities, and equip them to work with these children and their caregivers more effectively.

Strengthen capacities of service providers across sectors

All service providers, including health care workers, child protection officers, educators and others working with children and families should be knowledgeable about health-related (e.g. low birth weight, undernutrition) and psychosocial (e.g. poverty, exposure to violence) risk factors for sub-optimal development and be able to recognize them as well as signs of developmental delays and disabilities. Health care providers should have competencies to identify health conditions associated with developmental delays and disabilities (e.g. Down syndrome, cerebral palsy) and establish a management plan or refer. Service providers (including those working in the community) should apply a family-centred approach so that they promote optimal child health; listen to caregivers' concerns without judgement; monitor children's development, promote participation, and follow up with appropriate interventions or referrals as appropriate; and promote caregiver health and well-being.

Early identification of children at risk of or with developmental delays and disabilities enables timely interventions. However, the requirement of a diagnosis should not delay access to family-centred services aligned with the needs of the children. With or without a diagnosis, all caregivers should be supported to provide their children nurturing care.

A baby with a doctor during a medical check and rehabilitation training in Tajikistan.
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SOUTH-EAST EUROPE

ATs give children a voice

Augmentative and Alternative Communication (AAC) systems have high potential to support young children with communication difficulties. They make it easier for children to express their needs and interests, thereby making it easier for their caregivers to understand and respond appropriately. However, in many settings, AAC systems, especially in local languages, are unavailable or unknown. UNICEF initiated and funded the “Giving Voice to Every Child” project in South-east Europe, supporting young children with communication impairments *(22)*. The project utilizes the Cboard AAC Solution, an open-source IT-based text-to-speech communication tool, and integrates a Global Symbols database with over 20 000 symbols. To promote the effective usage of Cboard in these countries and empower professionals and caregivers, UNICEF developed training programmes, using both in-person and online methods. The programme has been launched in Bulgaria, Croatia, Montenegro, North Macedonia and Serbia. Between 2019 and 2023, over 3000 children directly benefited from the project.

For more on ATs, see *(21)*.

Srna, 4, uses a Cboard Communicator (a free app) to talk about animals with her mother in Serbia.
© UNICEF Serbia/Vaš

INDIA

Equipping health care providers to monitor children's development

The international Guide for Monitoring Child Development (GMCD) provides a comprehensive, globally-applicable approach to child development in the context of the *Nurturing care framework*. The GMCD can be applied for all young children (from birth to 3-1/2 years of age); those developing optimally and those with risk factors, delays and disabilities.

In India, Ummeed Child Development Center and Mahatma Gandhi Institute of Medical Sciences have trained 675 community health workers and nearly 400 paediatricians on the GMCD, using materials to equip them to monitor and support development, and deliver ECI. The service providers now use this tool during their routine interactions with caregivers and children to counsel caregivers on how to promote their children's development. They also use the tool to conduct early identification and intervention for children at risk of or with developmental delays and disabilities.

Community health workers, nurses, family physicians, paediatricians, and ECI providers in over 30 countries have been trained to use the GMCD, and training of trainers has been completed in 14 countries. In Azerbaijan, Moldova, Kosovo and Turkmenistan – where services are centralized – it is being incorporated into the pre-service and in-service training of health providers and the national child health monitoring system. In India and Guatemala, not-for-profit organizations are working to incorporate it into community home visiting programmes. A cluster randomized controlled trial to evaluate the effectiveness of the GMCD in rural India and Guatemala is underway *(23)*.

For more information, see: https://www.gmcd.info.

A health worker counsels mothers about growth monitoring in India.
© UNICEF/UN0602881/Kaur

Empowered communities

Tackle stigma, myths and beliefs

False beliefs about these children may result in negative or exclusionary attitudes and behaviours towards them and their families. This may lead to them hiding or isolating themselves (by force or by choice), thereby limiting their interactions with community members and reducing their participation in activities (e.g., childcare, education). Actions should be organized to address these attitudes and behaviours and to share the lived experiences of children and their families to reduce stigma and isolation. Examples include: sensitization events held at health facilities, places of worship or other community spaces; community debates and dialogues; and using platforms such as theatre, film or music; as well as mainstream inclusion of children with developmental delays and disabilities in media campaigns, storybooks, television shows and radio programmes. (See country examples in Box).

In **Brazil**, a film about the lives of children with disabilities and their caregivers, *Um dia especial (A special day)* was shown followed by community debates. This intervention was effective in changing professionals' views about their practices *(24).*

In **Bangladesh**, **Pakistan** and **Thailand**, the Growing Together Project initiated by Humanity & Inclusion established parent clubs in refugee camps and host communities. Caregivers of young children with and without disabilities learned how to provide their children nurturing care. The project helped to break the stigma around disability *(25).*

In **Montenegro**, the It's All About Ability campaign addressed the social exclusion and discrimination of children with disabilities. A survey of Montenegrin citizens found that the campaign positively changed citizen's attitudes and increased the participation of children with disabilities in schools *(26).*

Facilitate utilization of community-based services

Places in the community meant for all children may intentionally or unintentionally exclude children with developmental delays and disabilities. Such places include childcare, early learning spaces, health clinics, places of worship, parks, markets, libraries and shopping centres. Efforts should be made to understand why children or their caregivers do not use these spaces and what can be done to make them more inclusive, accessible and welcoming. Adaptations to or better linkages across existing spaces, as well as the creation of new ones, may provide children and their caregivers with a sense of belonging and support. Examples include toy libraries with specially-adapted toys, places where caregivers can leave their child for a short period of time while they work or do self-care, quiet rooms, calming spaces, sensory areas in libraries, museums and recreational spaces; and peer support groups where caregivers can communicate with others and learn techniques to better care for themselves and their children (e.g. how to manage stress and conflict, caregiving practices).

Encourage bottom-up approaches to advocacy and planning

Persons with disabilities, organizations for persons with disabilities, parent or advocacy groups and other partners such as civil society, associations, academia and families can work together to advocate on behalf of children at risk of or with developmental delays and disabilities, shedding light on the experiences of such children and their caregivers. They can carry out media campaigns to highlight the importance and life-changing benefits of nurturing care, and also outline barriers to care and participation and demonstrate solutions. These stakeholders should be intentionally involved in priority setting, defining activities, and allocating responsibilities in national, municipal or district-level meetings. Solutions should be co-designed with stakeholders and caregivers so that services are tailored to needs.

A 7-year-old child diagnosed with severe hearing loss and neuropathy at age 2, attends a rehabilitation centre in Tajikistan.
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Caregiver capabilities

Responsive caregiver-child relationships, including through practising nurturing care, and support to caregivers during the earliest years of life are crucial for promoting early childhood development.

Gabriel, 7, diagnosed with autism at age 3, reads a book with his mother in Argentina.
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Encourage caregiver-mediated interventions

Caregiver-mediated interventions build confidence and skills to identify the unique strengths and abilities of a child and help children further develop competencies (e.g. for communication, social interaction and movement). They help caregivers appreciate what their child is capable of doing and equip them with the skills to have a positive and nurturing relationship with their child. Such interventions provide caregivers with strategies to engage their child in activities and communication, develop skills essential for daily living, and foster a positive sense of identity. They also promote mental health and well-being by promoting self-care, strengthening caregivers' confidence in their own abilities and creating opportunities for peer support. These interventions can be offered through home-based services, primary health care, community-based and outreach services or schools, as well as social and child protection services. (See example from Kenya).

Promote caregiver health and well-being

The physical and mental health and safety of caregivers and their access to resources affect their ability to care for their children. Without good mental health and support, caregivers may feel less able to carry out activities of daily living, including self-care and caring for and supporting their children. This can lead to negative outcomes including fewer opportunities to engage in interactions that promote development, unresponsive caregiving or harsh disciplining strategies. Service providers should be trained to promote caregiver health and well-being, enable caregivers to assess their own mental health and know when to seek attention, identify and respond to signs of mental health problems such as depression or anxiety, provide psychosocial support and make referrals for those who need additional help.

Strengthen caregiver-child interactions

In every interaction, service providers should be equipped to counsel caregivers on how to communicate with their child (e.g. social communication, sign language), understand and respond to their child's needs (e.g. verbal and non-verbal cues), play with their children using household materials (e.g. materials that make noise for a child with visual impairment) or adapted toys, responsively feed children with feeding difficulties, and promote children's inclusion and participation (at home, in preschool, recreational activities). Providers can also be equipped to recognize and address difficulties that could lead to negative outcomes for children and/or their caregivers (e.g. signs of stress or mental health problems, malnutrition, neglect, maltreatment of the child, financial insecurity of the family). In doing so, service providers can help caregivers to provide a nurturing and stimulating home environment and have positive interactions with their children. (See example from Asia).

Disseminate information on available services and support to caregivers

Caregivers often face numerous challenges in obtaining clear information about their child's diagnosis, how to care for their child, and available services and support. Information should be disseminated promptly and widely, via websites, parenting online portals or digital apps, or through posters, leaflets or radio. Vulnerable groups such as caregivers with disabilities or mental health conditions, those living in poverty, or those with a low level of literacy should be additionally supported with tailored strategies. Support could include who to contact about their child's development or care needs, and where to go for, e.g. peer support, financial aid, treatment, assistive devices or respite care. To the extent possible, individuals should be identified in the community, or a central point of contact, such as a hotline or a health clinic, should be created to act as a conduit of all relevant information. (See example from Uganda).

KENYA

Trained non-specialists increase caregivers' abilities to promote their children's development

WHO's Caregiver skills training (CST) for families of children with developmental delays and disabilities aims to increase caregivers' ability to promote their children's development and well-being through structured play and home routines *(27)*. The programme is designed to be delivered by trained non-specialists, such as community-based workers or peer caregivers, as part of a network of health and social services. The training adopts a family-centred approach to help care providers support caregivers of children aged 2-9 years with developmental delays and disabilities in defining specific training goals for each family. All children need nurturing care, and the package assumes that caregivers of children with developmental delays and disabilities can and should be supported in both tapping into their existing competencies and developing new skills that foster the child's learning, social, communication and adaptive behaviours. The CST package has been culturally adapted and translated for local communities and field tested or implemented in more than 30 countries.

In Kenya, for example, a sequential mixed methods study was carried out to test if it is feasible and acceptable to implement the CST package to improve behaviour, communication and quality of life of children with disabilities and their families in two resource-poor settings *(28)*. In the first stage, focus group discussion and in-depth interviews were carried out with key informants and parents of children with disabilities who observed that CST addresses an important need for the families of these children in their context. In the second stage, approximately 100 children living with a disability and their families were involved in a pilot randomized controlled trial (RCT). For parents who attended most of the sessions a decrease in behavioural problem scores for children who participated in CST and enhanced scores on family quality-of-life measures were observed.

In the post-CST exit interviews and focus group discussions, parents articulated their satisfaction with the programme,

"also for me the training helped me because I used to think that a child with disability, cannot do anything, I used to do everything for them. Bathing... like almost everything. But when I was taught I knew that a person with disability can help themselves to do so many things".

A large scale RCT is currently ongoing with collaborators from Addis Ababa University, Aga Khan University, Kenya Medical Research Institute-Wellcome Trust Research Programme, University of Oxford and King's College London *(29)*.

Karen, age 3, holds hands with her father in Kenya.
© UNICEF/UN066575/Ohanesian

Supporting caregivers of children with or at risk for cerebral palsy (CP)

Up to 80% of children with CP live in low- and middle-income countries where intervention resources are scarce. The Learning through Everyday Activities with Parents (LEAP-CP) programme aims to address this gap by providing contextually-appropriate intervention strategies for caregivers of children with or at risk for CP in low-resource settings.

LEAP-CP is a community-based, family-centred, caregiver-delivered early identification, intervention and education programme for children between 3 and 18 months of age at high risk of CP and their caregivers.

LEAP-CP is based on principles of coaching which promote problem-solving and self-determination and includes training caregivers to use activities and readily-available materials at home to promote motor, cognitive and literacy skills.

The education modules support caregivers to provide opportunities for early learning, adopt responsive practices, take care of their own mental well-being and the health and nutrition of their children.

The programme adopts an iterative coaching model. The Community Coordinator (health professional) coaches the Community Disability Worker (CDW) on new goals and activity targets for the child at a fortnightly training session and provides supported problem-solving of previous goals and activities via videos.

The CDWs are peer trainers from their local communities, with priority for employment given to mothers of a child with a disability.

The CDWs coach the caregiver (or other significant people in the child's life) on the goal or activity target at fortnightly home visits. Caregivers are the primary change agents for their children.

Providers from six countries including Bangladesh, Bhutan, India, Nepal, Sri Lanka and Viet Nam have been trained to implement the LEAP-CP programme locally, and a RCT for evaluating the effectiveness of the model is currently under way in India *(30)*.

For more information, visit https://cre-auscpctn.centre.uq.edu.au/article/2022/03/LEAPCPindigenous.

Father and son who has cerebral palsy enjoy a walk in their neighbourhood.

Routine immunization is used as a platform for early identification and intervention for developmental delays and disabilities in Uganda.
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UGANDA

Ubuntu [Togetherness]: a non-profit shared learning hub

‘Ubuntu’ embodies the African philosophy of ‘togetherness’, or a sense of “I am, because we are”, and is deeply rooted within cultural concepts of community and humanity in many countries and languages across Africa. The Ubuntu Hub is a non-profit, shared learning hub supporting three programmes: Ubuntu for older children with developmental disabilities, Baby Ubuntu for at-risk children 0-3 years, and Juntos for children affected by Congenital Zika Syndrome. These modular, group, participatory programmes are co-facilitated by a health care worker and an expert parent, who is a caregiver of a child with developmental disabilities, and places emphasis on a participatory approach to learning at community level. The programmes aim to promote inclusion and participation for children with developmental disabilities within the family and community by equipping caregivers with the skills and confidence to maximize their child’s developmental potential, health and quality of life. They aim to promote empowerment of caregivers through information exchange and shared maternal experiences (peer support) to address stigma and promote the rights of children with disabilities.

In Uganda, the Baby Ubuntu programme has been found to be feasible and acceptable in both urban and rural settings with strong qualitative evidence of impact. It is currently being implemented across central and western Uganda where mixed-methods evaluations have shown a 15-25% increase in family quality of life in pre-/post evaluations. Additional modules have recently been developed to specifically address participation and inclusion, and the need for livelihood support for families in poverty. A tablet application with embedded monitoring, evaluation and learning platform is being piloted and a cluster randomized trial, with embedded process and economic evaluations, will be completed in 2026.

The Ubuntu-Hub programmes have been implemented in many countries, including Bangladesh, Brazil, Colombia, Ghana, Rwanda and Uganda, and is supported by a Community of Practice of more than 560 practitioners across 90 countries and territories.

For more information, visit https://www.ubuntu-hub.org/.

Conclusion

The *Nurturing care framework*, aligned with the Sustainable Development Goals, seeks to build a continuum of care to support all families of young children based on their needs. This can be done by ensuring children with developmental delays and disabilities are included in studies and surveys so that data can guide policy and programming. Efforts are needed to ensure services in health and other sectors promote optimal development, prevent exposure to risks and identify and address the needs of those children and caregivers requiring additional support. For those children at risk of or with developmental delays and disabilities, service teams and coordinated services across sectors should work together to ensure care is provided according to the needs of individual children and their caregivers. In doing so, all children can receive nurturing care and develop to their full potential.

Remember

Nurturing care, the right of every child, can protect children who are exposed to risk factors as well as improve functioning and long-term outcomes of children with developmental delays and disabilities.

Strengthen

Enabling policies, inclusive mainstream and targeted services, empowered communities and supported caregivers ensure that all children, including those at risk of or with developmental delays and disabilities, receive the support they need.

Add

Adopting a nurturing care lens puts children and their caregivers at the centre, thereby ensuring services across different levels. Existing caregiver practices across all components of nurturing care will be reinforced, caregivers will be supported to develop new ones, and equipped with the knowledge and resources to better care for themselves and their children.

Selected resources

Networks

Early Childhood Development Action Network: disability inclusion
https://ecdan.org/ecd-knowledge-gateway/disability-inclusion/

Early Childhood Development Taskforce Resource Hub
https://ceinternational1892.org/ecdtf/

Global Research on Developmental Disabilities Collaborators
https://www.under5disabilities.org/

International Disability Alliance
https://www.internationaldisabilityalliance.org/

Publications

Global report on children with developmental disabilities
https://www.who.int/publications/i/item/9789240080232

Global report on health equity for persons with disabilities
https://www.who.int/publications/i/item/9789240063600

Data

Data on children with disabilities
https://data.unicef.org/resources/children-with-disabilities-report-2021

Implementation resources

Accessibility toolkit
https://accessibilitytoolkit.unicef.org/

Caregivers Skills Training for families of children with developmental delays and disabilities
https://www.who.int/teams/mental-health-and-substance-use/treatment-care/who-caregivers-skills-training-for-families-of-children-with-developmental-delays-and-disorders

Community-based rehabilitation: CBR guidelines
https://iris.who.int/handle/10665/44405

Disability inclusive and accessible child friendly spaces in humanitarian action: guidance for the East Asia and Pacific region
https://www.unicef.org/eap/disability-inclusive-and-accessible-child-friendly-spaces-in-humanitarian-action

Methodological guide: research for national situation analyses on early childhood intervention
https://www.unicef.org/eca/media/28481/file/Methodological%20guide:%20Research%20for%20national%20situation%20analyses%20on%20early%20childhood%20intervention.pdf

Toolkit on disability for Africa: building multistakeholder partnerships for disability inclusion
https://www.un.org/esa/socdev/documents/disability/Toolkit/Building-multi-stakeholders.pdf

Development of this *Brief*

To develop this *Brief*, a UNICEF-WHO task team was established comprising technical leads with expertise in child development, developmental delays and disabilities and early childhood intervention services. A reference group comprising diverse stakeholders (international organizations, academic institutions, and organizations of persons with disabilities) was established in 2021. This group met four times between September 2021 and December 2024 to prioritize key messages and actions to be included in the *Brief*, guide the identification of country examples and selected resources to be featured, and provide their technical guidance and inputs on the drafts.

The International Centre for Disability and Rehabilitation (ICDR) at the University of Toronto was recruited to define the scope and contents of the *Brief* and develop a first draft (September 2021 – May 2022). Applying a participatory and consultative process, the ICDR University of Toronto contacted members of its network and a list of stakeholders (government, thematic experts, organizations of persons with disabilities) provided by the task team, and conducted caregiver focus group discussions in India, Malawi, and Sierra Leone (conducted by local facilitators and in the local language). The purpose of the consultations was to identify key issues, country examples, and recommended actions for inclusion in the *Brief*. The consultations were complemented by a desk review of published peer-reviewed and grey literature. All findings were reviewed with the reference group.

Development of the *Brief* went through multiple iterations building on the first draft developed by ICDR University of Toronto. Subsequent drafts were developed by independent contributors supported by the task team, reference group and peer reviewers. The final manuscript was reviewed and endorsed by the reference group.

Declarations of interest were requested from all external reviewers, contributors and reference group members. No significant conflicts were identified.

Silah, 1, who has Down syndrome receives rehabilitation and training in Pakistan.
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A young boy enjoys playing on swing in South Africa.
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Nurturing care framework for early childhood development

The *Nurturing Care Framework for early childhood development: A framework for helping children SURVIVE and THRIVE to TRANSFORM human potential (20)* builds on state-of-the art evidence of how child development unfolds and of the effective policies and interventions that can improve early childhood development. WHO, UNICEF and the World Bank Group developed the *Framework* in collaboration with the Partnership for Maternal, Newborn & Child Health, the Early Childhood Development Action Network and many other partners to provide a roadmap for attaining the Sustainable Development Goals and the survive, thrive and transform goals of the Global Strategy on Women's, Children's and Adolescents' Health. Launched alongside the Seventy-first World Health Assembly in May 2018, it outlines: i) why efforts to improve health and well-being must begin in the earliest years, from pregnancy to age 3 years; ii) the major threats to early childhood development; iii) how nurturing care protects young children from the effects of adversity and promotes physical, emotional and cognitive development; and iv) what families and caregivers need to provide nurturing care for young children.

FOR MORE INFORMATION

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A mother plays with her daughter in Peru.
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