# PARENTING SUPPORT FOR CHILDREN WITH DEVELOPMENTAL DELAYS AND DISABILITIES

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## LIST OF ACRONYMS

**CRPD:** Convention on the rights of persons with disabilities

**ECD:** Early childhood development

**ECE:** Early childhood education

**ECI:** Early childhood intervention

**FGM:** Female genital mutilation

**IPV:** Intimate partner violence

**OPD:** Organizations of persons with disability

**MHPSS:** Mental health and psychosocial support

**UNICEF:** United Nations Children's Fund

**UNICEF ECARO:** UNICEF Europe and Central Asia

**WHO:** World Health Organization

# ABOUT

Guoguo is playing with his parents in the Aijia Village of Dianjun District,Yichang City, China.

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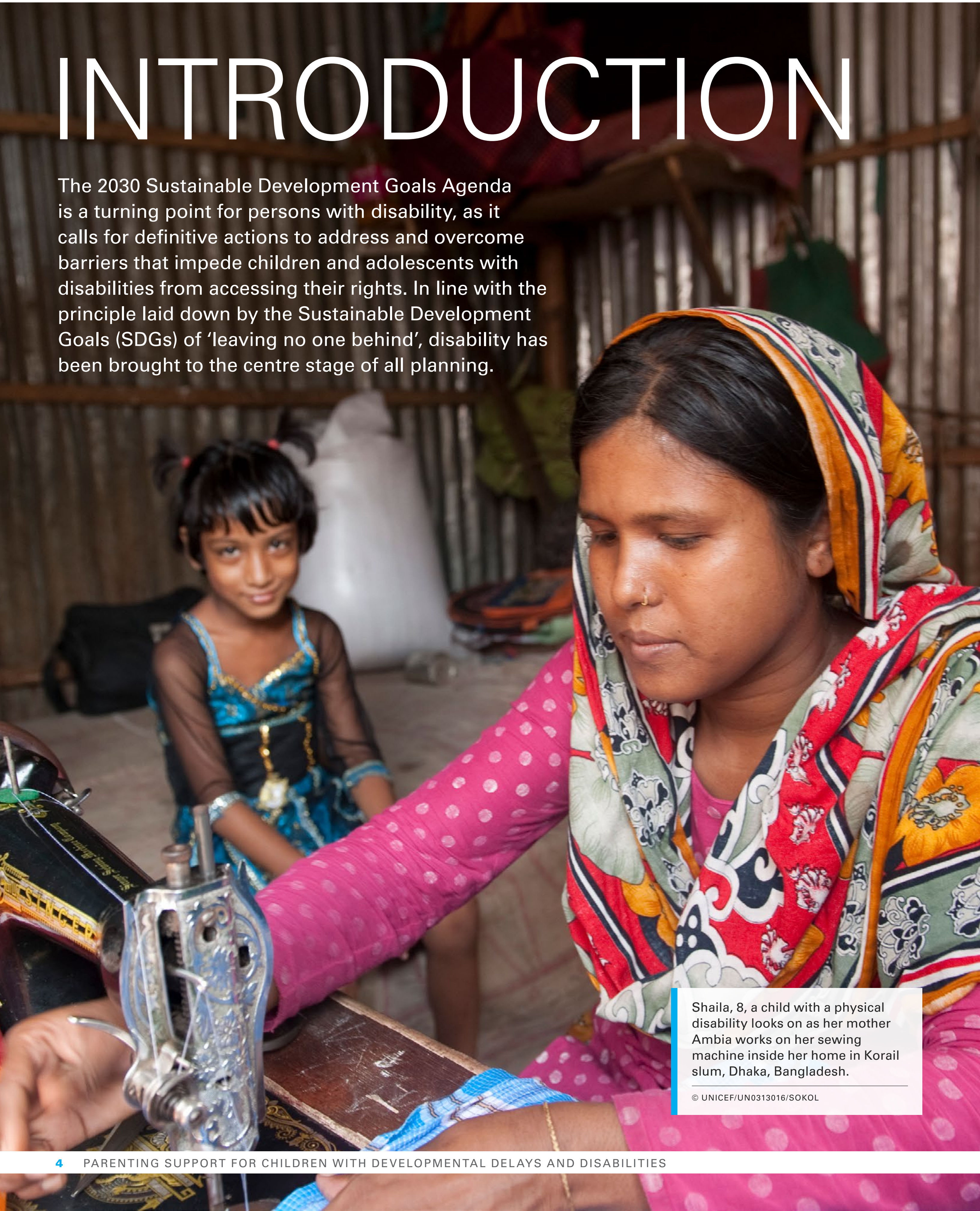
**Parents and caregivers are the best providers of nurturing care.** How well-versed they are in managing the complex needs of children with developmental disabilities and delays, and how readily they can access mainstream services such as health, nutrition, education, child protection and social protection, amongst others, will largely determine their journey of parenting. As the needs of each child with disability are unique as well as multifaceted, certain targeted interventions (like accessible and affordable trained professionals; and availability of assistive devices which make the child independent and make the parent relatively free) are also required.

The physical and mental health of the parents, their sense of personal effectiveness, financial comfort, and a community which embraces diversity will largely define and shape the parenting inputs and the development of a child with disabilities. This brief is about bringing to the attention of all state parties, policymakers, programme planners, implementers and communities parenting support strategies and interventions which can benefit parents and help them create better spaces for children with developmental delays and disabilities.

# INTRODUCTION

The 2030 Sustainable Development Goals Agenda is a turning point for persons with disability, as it calls for definitive actions to address and overcome barriers that impede children and adolescents with disabilities from accessing their rights. In line with the principle laid down by the Sustainable Development Goals (SDGs) of 'leaving no one behind', disability has been brought to the centre stage of all planning.



Shaila, 8, a child with a physical disability looks on as her mother Ambia works on her sewing machine inside her home in Korail slum, Dhaka, Bangladesh.

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Five out of the 17 SDGs make a reference to persons with disabilities, with 11 explicit indicators covering aspects such as:

- inclusive education
- access to information, health care and rehabilitation, basic infrastructure and services
- skills development
- social security
- employment
- data disaggregation based on disability for various parameters.

The SDGs provide a powerful framework for communities and nations to move towards developing disability-inclusive practices. The 2030 SDG agenda is aligned with the Convention on the Rights of Persons with Disabilities (CRPD), which is to incorporate the disability perspective in all aspects of its realization, monitoring and evaluation. This sentiment is aptly reflected in CRPD adopting the slogan, "Nothing About Us Without Us".[1]

In spite of an enabling framework provided by SDGs, and many efforts made by nations, things don't seem to have changed much for children with disabilities. According to a recent report, it is estimated that, globally, there are nearly 240 million children with disabilities. The global estimate is based on a subset of 103 countries and covers more than 60 indicators of child well-being. It confirms what the world already knew; children with disabilities continue to face multiple challenges like poor access to education, proper nutrition, learning opportunities, participation and protection from abuse, violence and harmful practices (*See Figure 1)*. These provide challenges that decelerate the chance for children with disabilities to realize their rights.[2]

Amongst all children and adolescents, those with disabilities are the most marginalized and excluded groups.[7] In families, guilt, shame and fear are frequently associated with the birth of a child with a disability.

Children with disabilities are frequently hidden from view, ill-treated and excluded from activities that are crucial for their development.[8] Starting right from the struggle to survive, they experience widespread violations of their rights; a dearth of educational and economic opportunities; severe social, economic, cultural and civic disparities; negative attitudes and stigma; and lack of adequate policies and legislations for their protection.[9]

## WHO ARE CHILDREN AND ADOLESCENTS WITH DISABILITIES? DEFINITION OF KEY CONCEPTS

The CRPD states that "**persons with disabilities** include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others".[3]

The International Classification of Functioning, Disability and Health: Children and Youth Version (ICF-CY) regards **disability** as neither purely biological nor social but instead the interaction between health conditions and environmental and personal factors.[4]

**Developmental delay** refers to children who experience significant variation in the achievement of expected milestones for their actual or adjusted age.[5] Delays can be temporary and the child's development may catch up when the situation improves.

It is not just the medical conditions that lead to **development disabilities**. The complex interaction between a health condition or impairment and environmental and personal factors contributes to how disability is perceived, as well as how its impact is managed, which means that each child's experience of disability is different.[6]

As a result of discrimination, children with disabilities have poor health and education outcomes; the barriers to engagement in civic life may be intensified for them, including access to employment; and they have low self-esteem and limited interaction with others.[10] They are at higher risk of facing violence, exploitation, abuse, neglect and harmful practices.[11] Moreover, girls with disabilities are at a higher risk of experiencing sexual and physical violence compared to boys with disabilities. Other forms of violence frequently faced by them include community violence and peer violence, including bullying, and slurs that they face.[12]

In accordance with the biopsychosocial model of disability, it is now widely recognized that disability arises not just from a person's impairments but rather the person's interactions with an environment which presents barriers to leading a dignified and fulfilling life. All persons, including those with disabilities, deserve to live their lives with dignity.

The challenges faced by children and adolescents with disabilities are also the challenges of their families.

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Recognizing this, it is fundamental to have adequate mechanisms for these families to access support systems; to have equal access to universally available services for their children; and to have targeted services which address specific needs arising from the disability.

## THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (2006)

### Preamble

"That persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities"

### Article 7

"In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration"

### Article 16.2

"States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender and age-sensitive assistance and support for persons with disabilities and their families and caregivers"

### Article 23.2

"Provide those health services [...] early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities"

### Article 26.3

"States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation"

### Article 28.2(c)

"To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care"

# DATA ON CHILDREN WITH DISABILITIES

The availability of data on children with disabilities has been a long-standing challenge due to the limitations of narrow definitions and the lack of a standardized methodology for data-collection.[13] When absent from official statistics, children and adults with disabilities remain politically and socially 'invisible'.[14] As a smaller number gets reflected in the data, this also results in lower budgetary allocations for children with disabilities.

Fahiem Abrahams, 37, plays with his son, Fawad (in red), 4, and son Mika-eel (in black), 3, at their home in Bonteheuwel, Western Cape, South Africa. Fawad, who lives with autism, communicates primarily through musical intonation rather than words.

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Further, country-level data available on disability do not always allow comparisons between those with disabilities and those without. Also, the data collected are not always disaggregated, and therefore may not often give information on the disadvantages faced by women with disabilities, children with disabilities, older people with disabilities and so on. In several countries even when data on disability are collected, they are not published.[15] Additionally, global experts have called for accurate, culturally relevant and robust data.[16]

In addressing the need for robust data on children with disabilities, of particular relevance is the Washington Group/ UNICEF Module on Child Functioning.[17] The measures were specially designed to be internationally comparable and to allow the SDGs to be disaggregated by disability.[18]

A recent global publication is *Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities, published by UNICEF in 2021, employed the Washington Group CFM to collect data.*[19] The publication provided evidence that children with disabilities face more negative health and nutrition outcomes, receive less responsive care from parents, have worse learning outcomes and face much greater violence and abuse, as is reflected in the following data (*See Figure 1*).

Discrimination based on gender is a critical issue in and of itself, but the effect is compounded when a girl or woman has a disability. Globally, 68 per cent of girls and 30 per cent of boys with developmental or intellectual disabilities are likely to experience sexual abuse before their eighteenth birthday.[21] Compared to boys, girls with disabilities are more

**FIGURE 1:** Data on children with disabilities[20]

Global estimates show there are 240 million children with disabilities (2–17 years). Compared to children without disabilities, children with disabilities are:

**HEALTH**

**1.9x** more likely to have diarrhoea
**1.6x** more likely to have symptoms of acute respiratory infection
**1.4x** more likely to have a fever

**NUTRITION**

**34%** more likely to be stunted
**25%** more likely to be wasted

**PROTECTION***

**3.7x** more likely for combined measures of violence
**3.6x** more likely for physical violence
**2.9x** more likely for sexual violence

**EARLY CARE & EDUCATION**

**25%** less likely to receive early stimulation and responsive care
**25%** less likely to attend early childhood education
**42%** less likely to have foundational reading and numeracy skills
**49%** more likely to have never attended school
**47%** more likely to be out of primary school

**Source:** United Nations Children's Fund, *Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities*, UNICEF, New York, 2021; *Liverpool John Moores University, and World Health Organization, *Violence Against Children with Disabilities*, WHO, n.d, United Nations Children's Fund cited in *The State of the World's Children: Children with disabilities*, UNICEF, New York, May 2013 likely to be excluded from family interactions and activities, and less likely to receive health care or assistive devices. While boys with disabilities are expected to get a job and live independently, families have lower expectations of girls.[22] Girls with disabilities are also less likely to receive vocational training, get educated or be employed, compared to boys with disabilities, or girls without disabilities.[23]

The discrimination experienced by children with disabilities worsens in times of calamities, conflicts and pandemics. Save the Children conducted a large-scale study based on a representative sample of 17,565 parents or caregivers and 8,069 children (aged 11–17).

Participant groups were drawn from 37 countries. The hidden impact of Covid-19 on children and families with disabilities was studied and the major findings were:[24]

- 44 per cent of children without disabilities and 55 per cent children with disabilities were playing less.
- A higher percentage of children with disabilities reported an increase in negative feelings (86 per cent), showed signs commonly associated with distress (69 per cent) and violence at home (43 per cent) when compared with reports from children without disabilities (83 per cent, 47 per cent and 15 per cent, respectively)
- 1 in 3 caregivers of children with disabilities reported that the children did not have access to any learning materials.

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**CASE STUDY 1.**

## JORDAN: UNICEF'S INCLUSIVE EDUCATION WORKSHOPS[25]

To support children with disabilities in Jordan during the coronavirus pandemic, UNICEF provided disability-inclusive workshops in camps and host communities on Mathematics, Arabic and perceptual and sensory skills. This was accompanied by videos for parents to use with their children for speech and occupational therapy during the lockdown.

Support facilitated by the Ministry of Education was given through community volunteers on WhatsApp called 'shadow teachers'. Special permission was obtained by UNICEF to allow these teachers to continue monthly home visits in the camps.

Close to 1,000 children with disabilities in the camps used these services. Transparent face masks were used to allow lipreading for better communication without compromising safety.

UNICEF also provided pre-loaded tablets to 80 families in the Azraq camp. These tablets contained learning resources and facilitated the development of educational and digital skills when schools were shut.

# CHALLENGES PARENTS FACE

Parents and caregivers include mothers and fathers (biological as well as step parents and adoptive parents), siblings, grandparents and other relatives involved in caregiving. Parents provide nurturing care to the child in an emotionally supportive environment with opportunities to play, interact, communicate, explore and learn, all in a safe and secure space.

Maria Alexandrova, her mother, Zornitsa Bosilkova, and her best friend, Vanessa Georgieva, walk in front of the Tower of the Meshchiite downtown Vratsa, Bulgaria. Maria, 17 years old, living with cerebral palsy, is an advocate for other adolescents with disabilities in Bulgaria.

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Parents help build the architecture of their children's brains through responsive interactions, hence laying the foundation for physical health, lifelong learning, executive functions and psychosocial well-being. 'Parenting' refers to the "interactions, behaviours, emotions, knowledge, beliefs, attitudes and practices associated with the provision of nurturing care".[26] The quality of parenting practices is the key to good development outcomes.

Parenting is a challenging job, and the challenges mount when it comes to a child with disability. Challenges experienced by parents of children with disabilities include:

- excessive workload demands which reduce their free time and lower their quality of life[27]
- lack of money due to job loss and added expenses of assistive devices, transport and medical care[28]
- mental health issues like stress, anxiety and depression (at times 'chronic' depression)[29]
- feelings of stigma, discrimination and isolation, with some facing a negative narrative on disability in communities.[30]
- low social support and low connection to parent networks or organizations of people with disability
- inadequate information about services available for children with disabilities.[31] They spend a lot of time in trying to find the availability of and access to services.

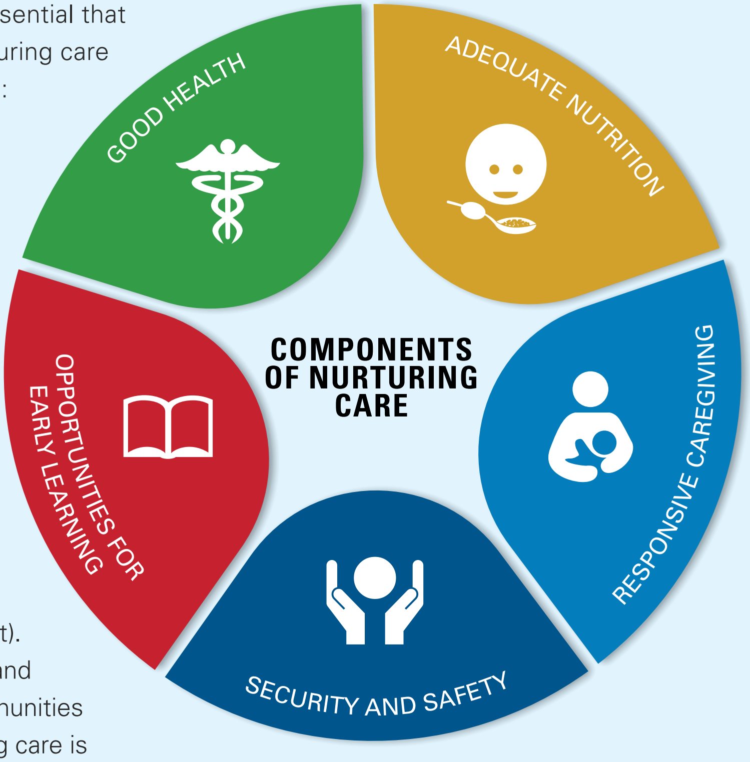
While it is important that parents should be supported with information on best practice, it is, at the same time, equally important to appreciate that parents too have needs (e.g., mental health, financial, social) that can't be ignored. Parents need support and care so that they are able to provide the best possible care for their child with a disability, appreciating that they are creators of safe and balanced environments for their families.[32]

## NURTURING CARE FRAMEWORK

For children to develop to their full potential, it is essential that parents and caregivers provide nurturing care. Nurturing care comprises five distinct but closely related elements:

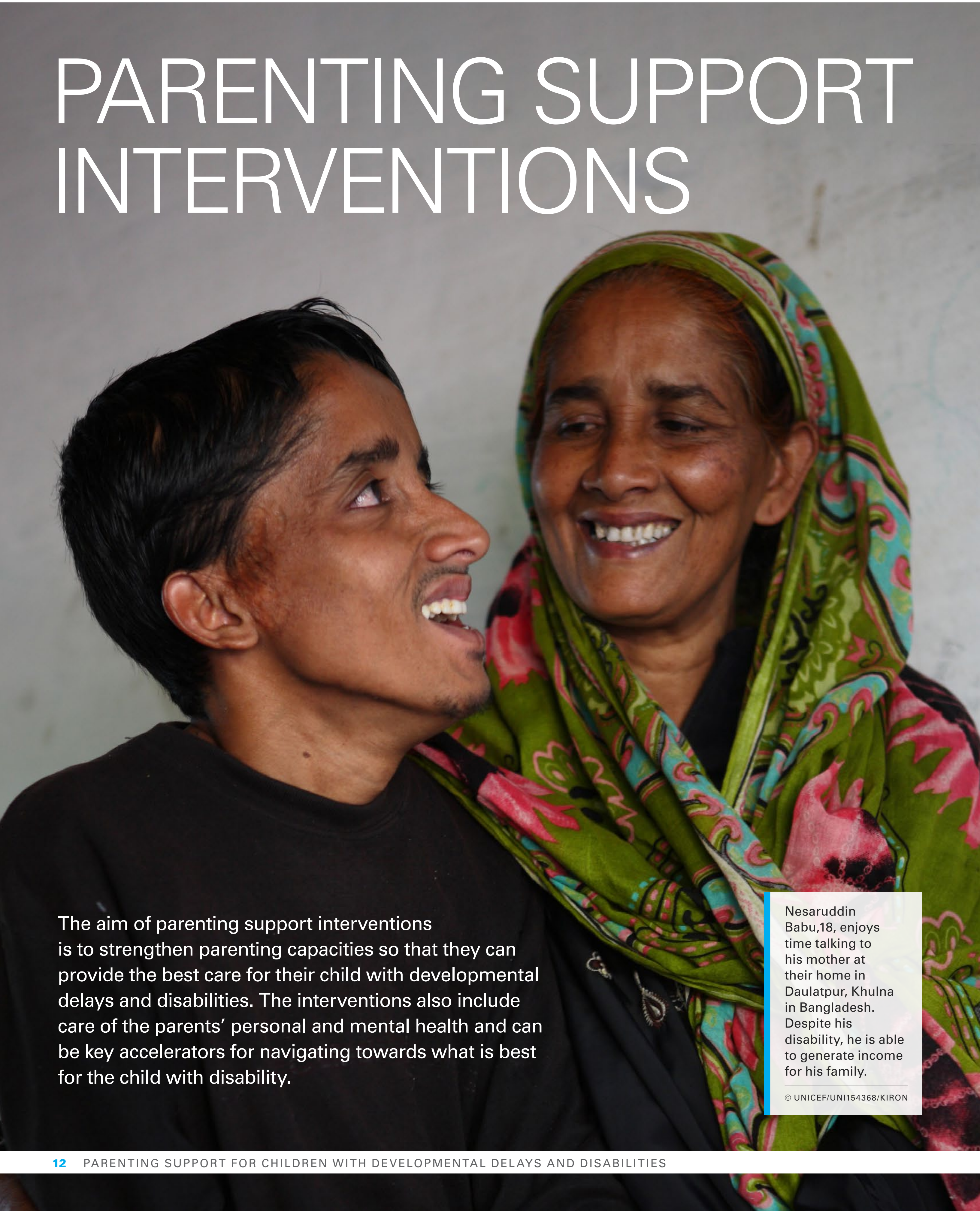
- adequate nutrition
- good health
- responsive caregiving
- opportunities for learning
- safety and security.

The ideal environment is one where the child's nutritional and health requirements are met (e.g., feeding, hygiene, health care); where interactions are responsive, stimulating and supportive (e.g., attitudes, behaviour, knowledge about caregiving); where plenty of opportunities of learning are present from early on (e.g., playing, singing, talking) and where the child is protected from threats and violence (e.g., environmental pollution, abuse, neglect). Within this framework, public programmes, policies and services are designed to enable caregivers and communities to provide the above conditions.[33] Access to nurturing care is crucial to improving developmental outcomes for children with developmental delay and disability.



**Source:** United Nations Children's Fund, *UNICEF's Vision for Elevating Parenting: A strategic note*, UNICEF, April 2021

# PARENTING SUPPORT INTERVENTIONS



The aim of parenting support interventions is to strengthen parenting capacities so that they can provide the best care for their child with developmental delays and disabilities. The interventions also include care of the parents' personal and mental health and can be key accelerators for navigating towards what is best for the child with disability.

Nesaruddin Babu,18, enjoys time talking to his mother at their home in Daulatpur, Khulna in Bangladesh. Despite his disability, he is able to generate income for his family.

© UNICEF/UNI154368/KIRON

UNICEF's vision includes integrated, multilevel programming which moves beyond approaching parents as passive recipients of information or education. Instead, it views parents and caregivers as actively engaged in co-constructing support for their children as well as for themselves.[34] Parents and caregivers are seen as partners in programme design implementation and service provision. This shift may be particularly important for parents in strengthening their own knowledge and becoming more empowered.[35] This is especially relevant for parents of children with disabilities. Programmes build on the strengths of the parents, are culturally responsive and move away from adopting a deficit approach. Inclusivity is a key principle and nurturing care is supported for all children, explicitly including children with disabilities.[36]

Parenting support includes structured interventions with the primary focus on parents co-constructing and learning new skills that address parental knowledge and acting on attitudes, beliefs and practices. The interventions have the greater goal of improving parent-child interactions and the overall quality of nurturing care that a child receives. As children mature into adolescence, parenting relationships evolve. Parents require new, developmentally appropriate skills and strategies to meet their children's needs. Therefore, parenting support programmes should also include interventions for the emotional well-being of the parents.[37]

Parenting support builds on the principle of ensuring that inequities are addressed from the outset so that no child is left behind. Parents of children with developmental delays and disabilities need incremental levels of support, and families require more individualized and intensive services to improve the development of their children.[38]

Benefits of family-friendly policies, including leave for care of children with disabilities; breastfeeding support; inclusive, accessible, quality childcare; child benefits; pensions for caregivers; and early detection and intervention. This should be a part of parenting support interventions for families of children with disabilities.

Despite social norms becoming more progressive, most of the responsibility for childcare still falls on women. The imbalance in energy and time expended is significant when caring for children with disabilities and has an equally significant impact on the well-being and health of female caregivers.[39] Although mothers continue to be the primary caregivers, it would be worthwhile to include fathers in parenting support programs as well. Recognizing that disability impacts girls more, parenting support interventions also need to be gender responsive.

## GENDER RESPONSIVE PARENTING

Parenting that applies key principles such as gender equality and inclusion, and that promotes positive gender norms and socialization, in order to transform imbalanced power structures in families (and future generations) is known as **gender-responsive parenting.**

Examples would include ensuring girls and boys are provided with equal and adequate nutritional and health services. Another is ensuring the equitable availability and distribution of resources and opportunities for all children of all genders and abilities, e.g., digital devices for remote learning at home.

Ending gender-related harmful practices at home are also part of this kind of parenting. These practices include gender-based domestic violence, but also gender-bias such as telling boys that they cannot cry and making girls (but not boys) take on caregiving and domestic tasks at home. As children move to adolescence, restrictions on female mobility or the stigmatizing of menstruation as 'impure' or 'taboo' are also some gender-biased discriminatory practices.[40]

# THE LIFE-COURSE APPROACH

A life-course approach acknowledges that most life stages or transitions are social constructs that are neither finite nor irreversible.

It recognizes that all stages of a person's life are intricately linked with each other as well as the lives of other people in society and with past and future generations of their families. It is increasingly used in the analysis of epidemiological and health trends.

Ljiliana Randjelovic holds her two-year-old foster daughter, Natalija Dinic, at their home in the city of Niš. Natasha was born with Down's Syndrome and a heart problem in a place without support or counselling for parents of disabled children.

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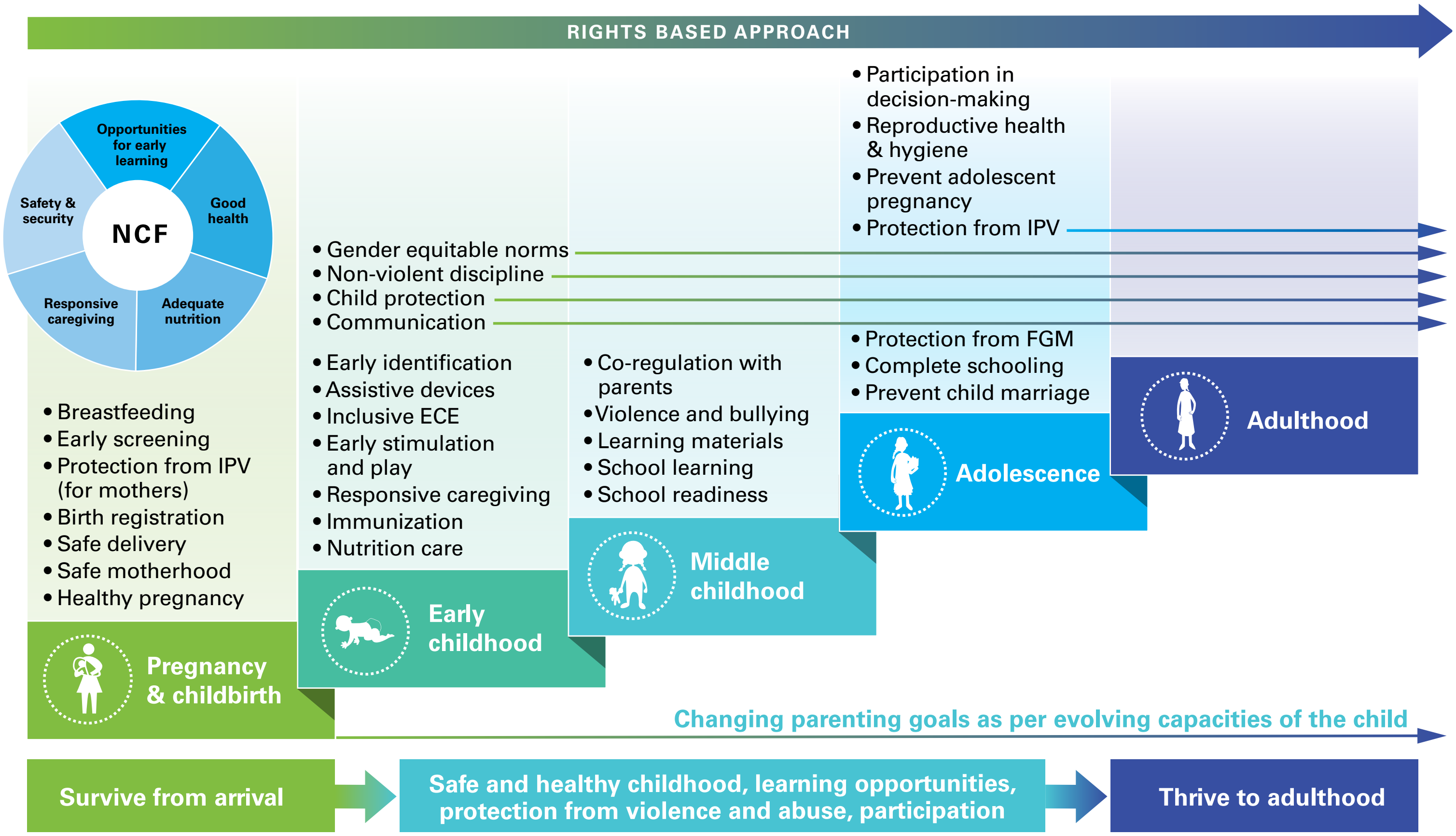
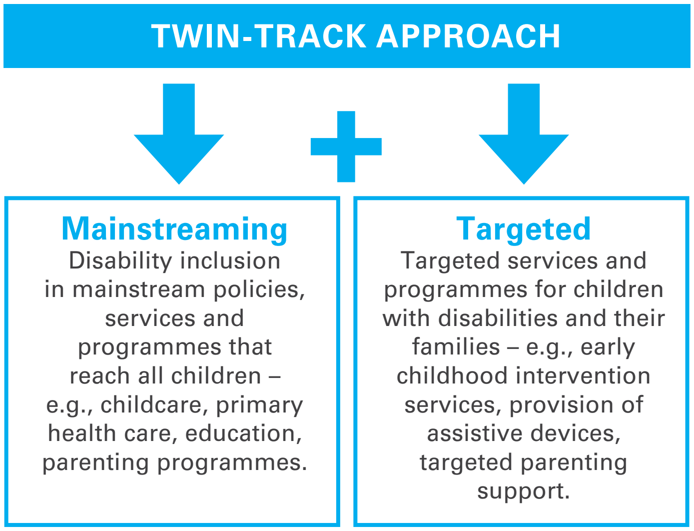
**FIGURE 2:** Life course development: Transition of needs from birth to adolescence of all children



This figure reiterates the importance of enriched environments for overcoming developmental delays and disabilities. This approach advocates continued support across the life course, matched to a child's needs at each development stage.

The life course approach helps to bring out needs and challenges of each stage, while the proposed twin-track approach of UNICEF and World Health Organization (WHO) is a blended approach. It proposes that families make routine contacts with mainstream health, nutrition, education, child protection, social welfare and other services to address needs of children with disabilities.

There should be an effort to make these routine services disability-sensitive and disability-inclusive, providing the required support throughout the life course in all key developmental areas. Simultaneously, these services can be complemented by specific targeted interventions like early detection and early intervention (*see Case Study 2);*[41] inclusive education; the provision of assistive devices; respite care; and targeted parenting support for the families with children with developmental delays and disabilities, among others.[42] The twin-track approach can be adopted to address challenges faced by children across the life course challenges faced by children with disabilities and

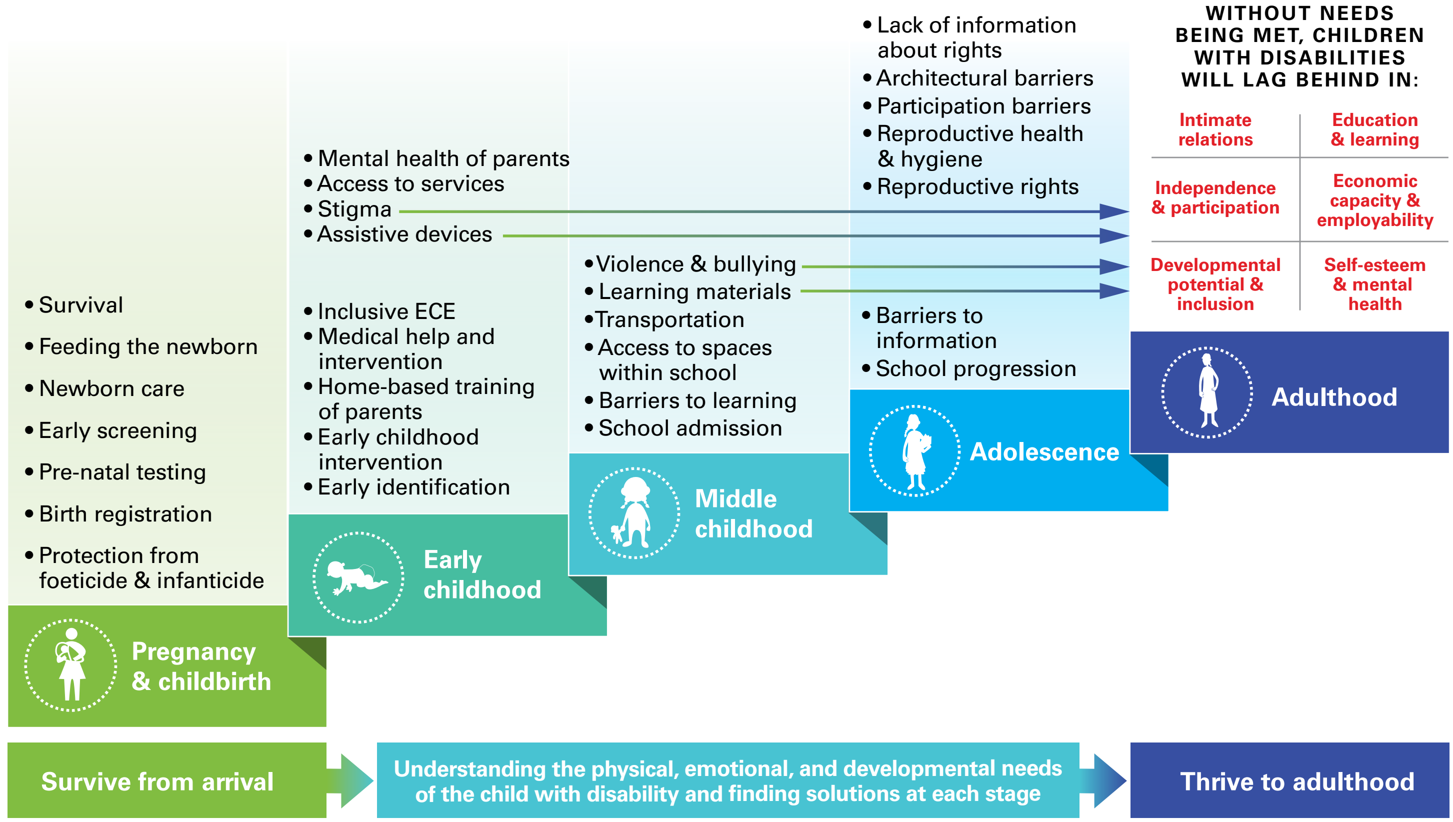

**TWIN-TRACK APPROACH**

**Mainstreaming**
Disability inclusion in mainstream policies, services and programmes that reach all children – e.g., childcare, primary health care, education, parenting programmes.

**Targeted**
Targeted services and programmes for children with disabilities and their families – e.g., early childhood intervention services, provision of assistive devices, targeted parenting support.

**Source:** United Nations Children's Fund, *UNICEF's Vision for Elevating Parenting: A strategic note*, UNICEF, April 2021

**FIGURE 3:** Life-course challenges in the development of children with disabilities (targeted concerns)



to find targeted responses to those challenges. Figure 2 depicts the life course challenges which are common for all children, while Figure 3 portrays the challenges more specific to children with disabilities. Twin-track interventions (mainstream and targeted) can be woven around these challenges.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### CASE STUDY 2.

## UGANDA: ABAANA EARLY INTERVENTION PROGRAMME[41]

The ABAaNA early intervention programme studied early neuro-developmental outcomes which arise after neonatal encephalopathy in Uganda.

The ABAaNA programme was adapted for children aged 0–2 years, and aimed to improve parenting skills and knowledge with a participatory and empowering approach.

The ABAaNA programme was peer-led in group settings at the community level. Each group consisted of 6–10 families and training was provided through modules on understanding disability, mobility, training, feeding, communication, positioning and carrying the child, play and local community experiences.

Each module session lasted 2–3 hours, with time included for facilitated discussion, and was delivered every 1–2 weeks. The programme's core themes included:

- promoting the human rights of children with disabilities
- endorsing their participation and inclusion within community and family
- optimizing their potential for development, health and quality of life
- promoting the empowerment of caregivers through peer support and information-sharing
- understanding the experience of the child and family, including addressing stigma.

Families enrolled in the course were encouraged to problem-solve together, collectively reflect and share experiences with each other. Group sessions were facilitated by 'expert parents' who also had children with neurodevelopmental impairment, and had undergone training. The delivery of the full programme was intended to take six months, and included a minimum of one home visit by an expert parent facilitator. Outcomes of interest were feasibility, acceptability, the quality of life of the child and the quality of life of the family. When piloted in an urban area in 2015–2016 among 28 families, there was a 25 per cent improvement in the quality of life scores for the families after the intervention.

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The SDGs indicate that people with disabilities are among the most marginalized and vulnerable population groups. The reports collected by international organizations reveal that disability itself is one of the main reasons why people with disabilities are lagging behind.[43]

# PARENTING SUPPORT STRATEGY

Anna Rosa Aniva stands with her son, Tercio Cangela, 4, in his wheelchair provided by UNICEF at their home in Beira, Mozambique.

© UNICEF/UNI310164/PRINSLOO

Children and adolescents with disability can face rejection, ridicule, a lack of opportunities to learn, play, access education and many essential services, and are mostly the lowest priority in the planning of most nations. Families regularly feel the brunt of widely-held misconceptions and stereotyped beliefs. Parents and the wider family play a vital role in caring for children with disabilities. Parents are critical pillars for building human capital in the first two decades of life.

Given below are some proposals for disability-inclusive parenting support strategies.

**TABLE 1:** Disability-inclusive parenting support strategies

| MAIN APPROACHES | KEY COMPONENTS WITH ILLUSTRATIVE EXAMPLES |
|---|---|
| 1 Strengthen parents' knowledge and skills to provide nurturing care and to respond to life-course challenges of children with disabilities | ● Nurturing care promotes the development of children with disability. Hence, it is very important to assess with parents the life-course challenges faced by a child with disabilities and to plan, co-construct and consult with them to build their knowledge and capacities to care for their child with disabilities (see Case Study 3).[44]<br>● As parents are the first point of contact with the child, they may identify signs of a disability (*see Figure 4*), way before anyone else, such as:<br>  ● a lack of startle response to loud sounds at birth<br>  ● no eye contact with caregiver while feeding<br>  ● an infant's babbling decreasing, rather than increasing between the age of 6–12 months<br>  ● delayed milestones of, e.g., sitting or walking.<br>  ● If parents ask for support, health workers should be sensitive to, and respectful of, their concerns.<br>● Responsive parenting (e.g., playing with the child) which is child-centred and respectful of a child's dignity, needs to be promoted, as do positive gender norms and socialisation.<br>● Non-violent discipline also needs to be encouraged, with an emphasis on the importance of safe spaces for children with developmental delays and disabilities.<br>● Parenting also needs to be promoted across the life course, as per the evolving capacities and specific needs of children (such as parents having access to counselling for appropriate feeding practices). As children grow up, parents need to collaborate with them to co-regulate and co-construct important decisions, like making decisions on appropriate independence for the adolescent child, or in defining sexual limits. As children with disabilities continuously face stigma, discrimination and abuse, co-create parenting strategies in consultation with the child, so as to build self-esteem. The programmes can also be made culturally sensitive and coherent by involving parents in making decisions right from the early stages of the programmes' design ideation, right up to its implementation. This way, a programme will take into account the disability needs of the children and will be tailored to the needs of the community it has been developed to serve.<br>● Leverage and invest in programmes that involve fathers and other members in caregiving activities. |

### CASE STUDY 3.

## GHANA: GETTING TO KNOW CEREBRAL PALSY[44]

This programme was aimed at empowering families via voluntary participation at community level.

Caregivers were invited to be part of support groups which provided training through modules on 'Getting to know Cerebral Palsy'.

Seventy-five caregivers from eight districts in Ghana were invited to join support groups of between eight and ten people. Each group met for an average of four hours a month studying modules covering a wide range of subjects, including communication, feeding, positioning and carrying, assistive devices and resources, play, everyday activities, evaluating your child, running a parent support group and disability in your local community.

These sessions were followed by short home visits and engagement with other family members. Training was voluntary and based on the principles of adult learning theory. The objective was to provide peer support and promote problem-solving and critical thinking. It included improving the care and support that could be provided to the child by the caregiver, enhancing the understanding of their rights and sharing their learning with other caregivers.

Thirteen facilitators went through a week-long master training and were paired to impart training to each support group. Each pair comprised a primary health worker and a physiotherapist or physiotherapist's assistant.

Attendance was quite high, with 92 per cent of all families attending all training sessions. At baseline, it was observed that common themes included low levels of knowledge, high levels of stigma, including self-stigma, high levels of emotional and physical exhaustion and difficult relationships within the family with social exclusion of the child and caregiver.

Two months after the intervention, caregivers reported an improved sense of well-being. This was based on an enhanced understanding of their child's condition, a positive shift in attitude towards their child, more hopeful feelings and, owing to the group support, a decreased sense of alienation.

**TABLE 1:** Disability-inclusive parenting support strategies *(continued)*

| MAIN APPROACHES | KEY COMPONENTS WITH ILLUSTRATIVE EXAMPLES |
|---|---|
| 2 Link parents and caregivers to mental health and psychosocial support services | ● Facilitate access to mental health and psychosocial support (MHPSS) services and programmes (such as counselling).<br>● Enhance access to platforms, organizations or support groups which facilitate conversation, messaging, knowledge exchange and collaboration on parenting of children and adolescents with disabilities.<br>● Leverage existing programmes to provide support in cases of intimate partner violence. |

**TABLE 1:** Disability-inclusive parenting support strategies *(continued)*

| MAIN APPROACHES | KEY COMPONENTS WITH ILLUSTRATIVE EXAMPLES |
|---|---|
| 3 Strengthen health systems and access to disability-inclusive health services | ● Strengthen services and programmes for mothers and child care to prevent disabilities. Make available affordable immunization and essential medicines for promotive health care. Ensure equitable access to health systems. Strengthen nutritional screening to prevent undernutrition and micronutrient deficiencies.<br>● Capacity building of community health workers and Early Childhood Development (ECD) workers to acquire simple skills for early detection of disabilities and developmental delays. This would also bridge the resource gap of trained service providers for disability needs, especially in the context of low- and-middle-income countries (LMICs). For example, the DIA (Detection-Inclusion-Ability) Training Module implemented in India followed the strategy of preparing a simplified module on early detection of disabilities (locomotor, visual, hearing and intellectual) and trained 120 community workers using the Module. Trained workers using a centre-based approach as well as home visits screened 13,000 children (birth to 6 years) and detected 921 (7.08 per cent) children with disabilities. These children were referred for early intervention. The results showed that suitably trained workers can serve as an essential bridge between children with disabilities and government services, creating a more integrated and coordinated system.[45] Countries can develop, test and roll out modules that can be integrated into health worker training packages.<br>● Implement a policy of mandatory national annual screening for disabilities in ALL children by trained community workers. Use opportunities when children come at key entry points for detection like primary health centres, creches and preschools (*see Case Study 4*).[46] It is important to note that children who don't have access to health services, or who are not attending preschool, are less likely to be identified early. Home visits for identification would be required in such cases (*see Figure 5*).<br>● Offer clear referral pathways so that early detection can be followed by early intervention. For example, community-based initiatives, such as Village Health Nutrition Day, provide first-contact primary health care that is crucial in identifying disabilities and providing immediate intervention and referral to specialized services. This is particularly important for children with disabilities and their families living in hard-to-reach areas.[47]<br>● Service delivery of interventions should include centre-based and home-based care. For example, community workers can make home visits to share strategies for the proper positioning of a child with cerebral palsy, using locally available material.<br>● Early medical intervention services to minimize disabilities should be readily available in hospitals.<br>● Countries should have a 'model of community-based services', where a repository of affordable and accessible disability support professionals (such as speech therapists and occupational therapists) are available.<br>● Where digital access or geographic access is a challenge, provide remote delivery of disability-inclusive health, nutrition and education services through traditional methods like home visits, community radios, etc.<br>● Rehabilitation units can be set up to innovate assistive devices and find affordable solutions for improving functionality of children with disability. |

**FIGURE 4:** Early signs of visual and hearing disability[48]

## EARLY SIGNS OF VISUAL IMPAIRMENT

- Watering eyes or red eyes
- The white part of the eye has spots or is wrinkled
- Child not playing with his own hands or feet
- Child falls by tripping over objects while walking or crawling
- Eyes have a squint
- Scared or blurred eyes
- Child is not making eye contact while talking or feeding
- Child not reaching for objects in the visual field
- Child not able to see in the dark

## SIGNS OF HEARING IMPAIRMENT

*Is the answer 'NO' to the following?*

- If you clap at a distance of about three feet from the infant, does the infant startle?
- Does the babbling of the infant increase between 8–12 months?
- Does a 12-month-old infant understand simple words like 'come'?
- When the child speaks, can you understand it?
- Does the child respond when she is called by name?
- By three years of age, has the child started talking?

*Is the answer 'YES' to the following?*

- Does the child explain any of it's needs through gestures?
- Is there frequent infection and discharge from the ears?
- Does the child frequently complain of earaches?

**Source:** www.earlydetectiondisabilities.com/Poster.htm

### CASE STUDY 4.

# LATIN AMERICAN AND CARIBBEAN COUNTRIES: CARE FOR CHILD DEVELOPMENT[46]

Childcare and family support services were identified as entry points for addressing families affected by the Zika virus when it started spreading in Latin America and the Caribbean in 2016.

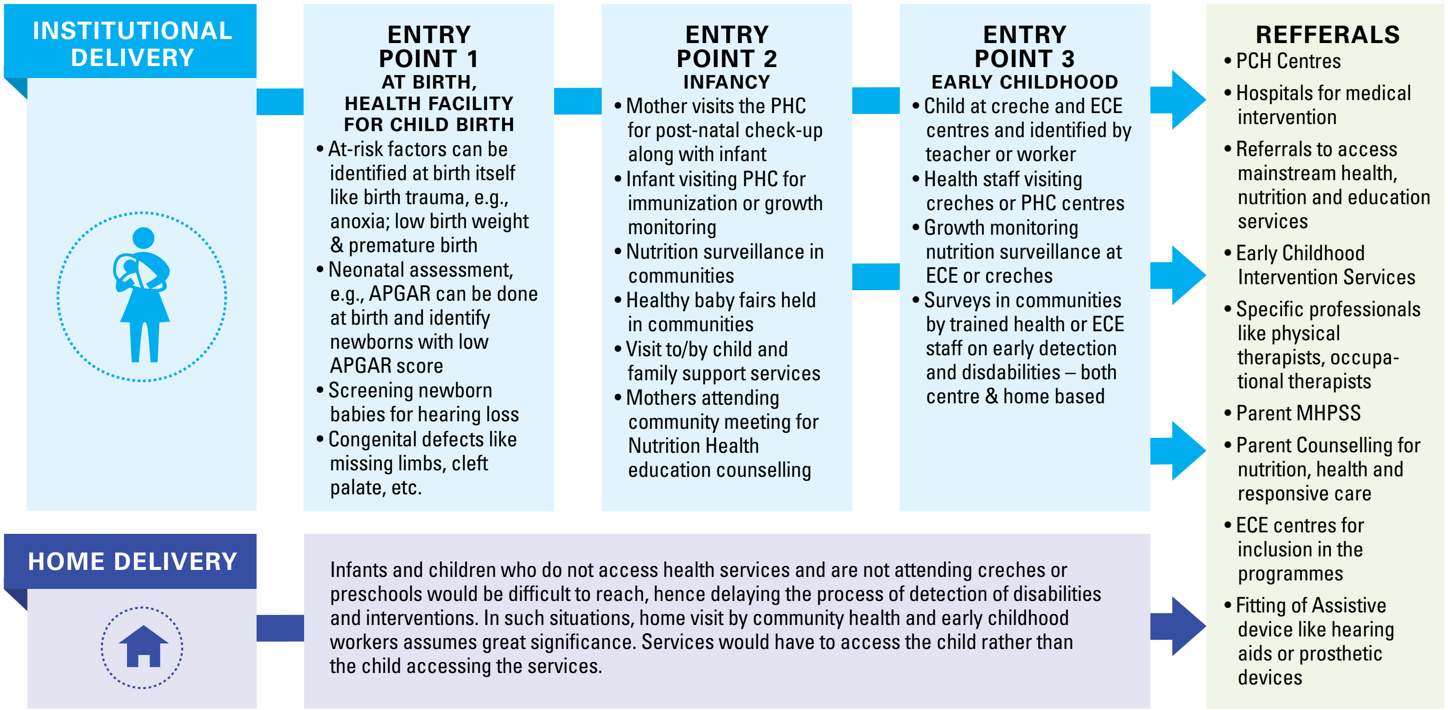
Care for Child Development (CCD) was used in eight countries over three years as part of early childhood interventions by promoting family inclusion, strengthening responsive caregiving practices and helping families in addressing the developmental and long-term health issues of the Zika syndrome and other congenital disorders.

CCD is aligned with nurturing care as it aims at strengthening the capacity of caregivers and families to engage in communication and play with children. It motivates caregivers to be sensitive and respond positively to children's signals, promotes interaction between children and their caregivers and learning opportunities and focuses on children's potential rather than children's limitations.

In the case of Peru, CCD materials were adapted to the Peruvian context, including the language and images used. Coordination between ECD workers and specialized child disability professionals was encouraged for the better delivery of services. The training included a module on disability identification, early care and practical sessions with children with disabilities.

In Peru, CCD has made a difference for 1,000 children and their families. Improvements were seen in health services as well as in early education. For example, previous educational interventions focused on activities led by teachers on how to interact with children, with parents as observers. However, after CCD was adopted, children interacted actively with their caregivers, with teachers contributing in a more supportive capacity.

**FIGURE 5:** Key entry points and referrals



**INSTITUTIONAL DELIVERY**

**ENTRY POINT 1**
**AT BIRTH, HEALTH FACILITY FOR CHILD BIRTH**
- At-risk factors can be identified at birth itself like birth trauma, e.g., anoxia; low birth weight & premature birth
- Neonatal assessment, e.g., APGAR can be done at birth and identify newborns with low APGAR score
- Screening newborn babies for hearing loss
- Congenital defects like missing limbs, cleft palate, etc.

**ENTRY POINT 2**
**INFANCY**
- Mother visits the PHC for post-natal check-up along with infant
- Infant visiting PHC for immunization or growth monitoring
- Nutrition surveillance in communities
- Healthy baby fairs held in communities
- Visit to/by child and family support services
- Mothers attending community meeting for Nutrition Health education counselling

**ENTRY POINT 3**
**EARLY CHILDHOOD**
- Child at creche and ECE centres and identified by teacher or worker
- Health staff visiting creches or PHC centres
- Growth monitoring nutrition surveillance at ECE or creches
- Surveys in communities by trained health or ECE staff on early detection and disdabilities – both centre & home based

**HOME DELIVERY**

Infants and children who do not access health services and are not attending creches or preschools would be difficult to reach, hence delaying the process of detection of disabilities and interventions. In such situations, home visit by community health and early childhood workers assumes great significance. Services would have to access the child rather than the child accessing the services.

**REFFERALS**
- PCH Centres
- Hospitals for medical intervention
- Referrals to access mainstream health, nutrition and education services
- Early Childhood Intervention Services
- Specific professionals like physical therapists, occupational therapists
- Parent MHPSS
- Parent Counselling for nutrition, health and responsive care
- ECE centres for inclusion in the programmes
- Fitting of Assistive device like hearing aids or prosthetic devices

**TABLE 1:** Disability-inclusive parenting support strategies *(continued)*

| MAIN APPROACHES | KEY COMPONENTS WITH ILLUSTRATIVE EXAMPLES |
|---|---|
| 4 Enhance access to quality inclusive education | • Promote inclusive education and make, as a right, education accessible for ALL children at all levels.<br>• Support and build the capacity of teachers, starting from early childhood education, to adapt to the learning needs and learning styles of children with developmental delays and disabilities (e.g., teaching the concept of a circle to a visually impaired child by using the sense of touch and 3D teaching aids).<br>• Adopt child-friendly, developmentally appropriate teaching-learning practices, adapting materials, using flexible curricula and spaces as per universal design for learning while maintaining safe learning environments, catering to a wide variety of learning styles, learning needs and personal preferences.[49]<br>• Ensure transport access to learning centres at all life-course stages. Remove the barriers hampering children with a disability from attending school.<br>• Provide access to teaching-learning materials and innovative technology for supporting the education of children with developmental delays and disabilities (*see Case Study 5*).[50] A study assessed the impact of technology-enhanced storytelling (TES) designed to support parent-child interaction and vocabulary in preschool children. The TES involved the use of a tablet for real-time auditory, visual and textual prompts in story narration. It generated active child involvement and stimulated parent-child interaction. The use of prompts was associated with higher quality parent-child interaction while narrating stories.[51] |

**TABLE 1:** Disability-inclusive parenting support strategies *(continued)*

| MAIN APPROACHES | KEY COMPONENTS WITH ILLUSTRATIVE EXAMPLES |
|---|---|
| 4 Enhance access to quality inclusive education *(continued)* | • Enable access to education in remote areas through digital and traditional delivery platforms. As part of ensuring that children with disabilities can access affordable textbooks in all contexts, UNICEF and its partners have launched the initiative *Accessible Digital Textbooks for All*. This adapts the principles of Universal Design for Learning, where the barriers to learning are assumed to be in the environment, not the student. The initiative enables textbooks to be given to a child with a vision disability, hearing disability or an intellectual, developmental or learning disability. It sets the standards for features like sign language, narration, interactivity and audio description of images.[52] |

### CASE STUDY 5.

## MONTENEGRO: FOR EVERY CHILD A VOICE[50]

UNICEF Europe and Central Asia (ECARO) and UNICEF Montenegro, in cooperation with the Ministry of Education and the Bureau of Education Services, has implemented this programme to ensure that children with communication impairments don't miss out on essential early childhood learning opportunities.

It is widely recognized that barriers to communication-related disabilities arise from not knowing how to use assistive technology with children, and a lack of appropriate and economical assistive technology solutions available in regional languages.

The For Every Child A Voice programme has found a way to combat this using an assistive technology for augmentative and alternative communication called C-Board, which:

- facilitates interaction
- helps overcome speech impairments
- develops language
- allows children to participate in social and learning activities.

This application allows children to communicate through symbols and enables text conversion to speech. It is also open-source, compatible with offline mode and available in more than 30 languages. It can be accessed online on tablets and smartphones by parents and children, and professional help is available in learning how to use it. It also has the added advantage that, in settings where access to technology is a problem, since the symbols are pictorial, they can be printed and used as paper resources.

The use of C-Board was intended as a routine-based intervention where carers and professionals are trained in the use of assistive technology and integrated as communicators in the child's schooling and home environment. User interviews have indicated that the app has also been useful in strengthening family bonds and enabling better communication. It has also led to improvements in competency, self-esteem and adaptability for the children.

**TABLE 1:** Disability-inclusive parenting support strategies *(continued)*

| MAIN APPROACHES | KEY COMPONENTS WITH ILLUSTRATIVE EXAMPLES |
|---|---|
| 5 Integrate disability-inclusive support in national systems and develop linkages | • Strengthen referral pathways and multisectoral service delivery by developing new partnerships and coordination mechanisms with ECI programmes and other early childhood services for example:<br>◦ health, e.g., provision of essential medicines and assistive devices<br>◦ nutrition, e.g., nutrition surveillance<br>◦ education, e.g., digital technology in schools for children with communication conditions<br>◦ social protection, e.g., budgeting for free wheelchairs<br>• child protection, e.g., sensitizing child protection officer that compared to other children; the child with disability is more vulnerable to violence and mal-treatment.[53]<br>• Encourage and support community-based rehabilitation programmes as these show the best outcomes in supporting families, as well as engaging communities. Often, this is the first support reaching families, especially in LMICs (*see Case Study 6*).[54]<br>• De-institutionalize care services for children with disabilities by establishing systems of alternative care and support to families, including respite care. This would mitigate the risk of burn-out in parents.<br>• Adopting and developing Family Friendly policies such as:<br>◦ disability scholarships<br>◦ transport allowances<br>◦ medical insurance<br>◦ allowances for families looking after people with disabilities<br>◦ financing disability-related expenses through health insurance.<br>• Participation of parents in community engagement, social accountability mechanisms and design and the delivery of policies and services, aimed at helping children with disabilities and their families.<br>• Provide workplace support to parents of children with development disabilities and delays.<br>• Engage with organisations of persons with disabilities (OPDs), including those that support family members of children with disabilities.<br>• Negotiate with families to ensure financial literacy and access to any available grants for financial augmentation and to support higher expenses due to disability-related costs. Build linkages with existing programmes to support the economic strengthening of families. |

**CASE STUDY 6.**

## INDIA: COMMUNITY-BASED REHABILITATION PROGRAMME[54]

In Karnataka, India, the Association of People with a Disability provides services including community-based rehabilitation (CBR) for children with cerebral palsy and their caregivers.

The rehabilitation programme involves home-based therapy sessions and parental training. These are aimed at improving the knowledge of parents on cerebral palsy, using therapy to handle their children, and making them aware about the rights of people with disabilities. In addition to rehabilitation, the programme promotes the use of assistive devices. Parent training helps mitigate the serious challenge of lack of accessible professionals in rural areas.

The study looks at the effects of the CBR programme on 100 parents of children with cerebral palsy. Their health, knowledge, social life, empowerment and home modification have been studied.

After completing the programme most parents reported a positive change in health. This included reports of reduced discomfort, reduced physical stress (e.g., handling, feeding, transfer, etc.), decreased anxiety and frustration and sufficient sleep at night. Most also said that, after the training, they:

- were comfortable taking care of their child
- could perform activities of daily living for their child
- had knowledge about cerebral palsy
- knew how to handle their children in proper ways
- had experienced a change in lifestyle.

The CBR programme also positively impacted the parents' social lives. Most of them found it easier to participate in social activities outside their home, such as attending religious and social functions, marriages and family gatherings. They got the time they needed for their own interests and needs, they did not feel neglected by their community and their family's attitude was more positive. On aspects of empowerment, most parents reported their awareness of the rights of people with disabilities (such as concessions, disability cards and specific facilities made available by the government) and being able to speak about themselves and their rights. As for the use of assistive devices, while there were no major changes found in toilet and home modifications, the use of wheelchairs, special chairs and orthotics improved children's mobility and positioning and reduced the physical burden on the parents.

### CASE STUDY 7.

## MALAYSIA: @KITACONNECT[55]

In the wake of the COVID-19 lockdown @KitaConnect is a disability-inclusive digital channel and was developed in 2020 by UNICEF Malaysia, the Childline Foundation and StudyHub Asia in response to the concerns and experiences of Malaysian adolescents and young people (including those with physical, learning, psychosocial, hearing and/or visual disabilities). This segment of the population had to rapidly adapt to online schooling, using the internet to learn how to protect themselves when seeking social interaction and connection online. The transition was particularly challenging for those with disabilities, as digital platforms were often inaccessible to them and caregivers were not equipped to provide digital learning assistance.

Based on RapidPro technology, @KitaConnect was designed as a dedicated virtual space to inform, connect, support and inspire action by and for young people. From the outset, the digital channel was made accessible and inclusive with options for closed captioning and subtitles, and was able to support sign language interpretation and language translation. The platform also strived to connect those with disabilities and those without disabilities by offering, for instance, sign language lessons for those with and without hearing impairments. Plans for the wider representation of young people's disability community involved including youth leaders from the special olympics in peer-to-peer trainings on topics of general interest, and building capacity for disability-inclusive content.

As of December 2021, the platform engaged 615,000 young people, including five per cent with disabilities, through youth chats, skills-building workshops and online @KitaConnect community and livestreaming platforms.

**TABLE 1:** Disability-inclusive parenting support strategies *(continued)*

| MAIN APPROACHES | KEY COMPONENTS WITH ILLUSTRATIVE EXAMPLES |
|---|---|
| 6 Improve access to information and services | ● Promote the use of digital platforms for parent training and give access to information on parenting children with disabilities, online resources and digital apps. Prepare a repository of professionals, the lists of which can be displayed on digital platforms.<br>● Use social networks and digital mediums to connect with other parents, and seek help for MHPSS (*see Case Study 7*).[55]<br>● Parents without access to technology need to be reached through alternative, community-based mechanisms such as home visiting, mobile platforms, radio, television and social work support – and they must also be reached in times of crisis. |

**TABLE 1:** Disability-inclusive parenting support strategies *(continued)*

| MAIN APPROACHES | KEY COMPONENTS WITH ILLUSTRATIVE EXAMPLES |
|---|---|
| 7 Make policies and laws and strengthen redressal systems | ● In line with CRPD, each country must have laws with a rights-based approach for children and people with disabilities.<br>● Each country should have national systems for redressal when the rights of children with disabilities have been violated. As an example, the Association of Youth with Disabilities in Montenegro, supported by UNICEF, provided legal and psychological support to 250 families of children with disabilities.[56]<br>● Each country should have disability-inclusive policies covering areas such as health and education. The impact of policies can be gauged by the example of the 'Zero Reject' policy in Malaysia, which contributed to the school enrolment of over 20,000 children with disabilities.[57] |
| 8 Enhance and improve data on children with disabilities | ● Countries need to strengthen data on children with disabilities; a first step would be registering their births.<br>● In national census taking, nations need to enumerate accurately the total number of children with disabilities.<br>● Disaggregated data on sex, age and disability need to be made available. Disaggregated data must also be collected on survival (e.g., the mortality rate for infants and children under five with disabilities), nutrition, health, access to services (e.g., how many visit health centres), education (e.g., enrolment and attendance), violence and participation (e.g., data on barrier-free cities and universal design in built spaces).<br>● Maintaining registers and records of children with disabilities makes them visible and improves participation. UNICEF has been providing support to the Government of Myanmar in the registration and certification of people/children with disabilities. This has led to the registration of approximately 60,247 children with disabilities and 123,434 people with disabilities.[58] |
| 9 Increase awareness generation | ● Increase awareness about CRPD and the rights of people and children with disabilities.<br>● Mobilize global awareness on the importance of providing parenting support as a key priority within countries.<br>● Raise community awareness about disability to reduce stigma and discrimination and make communities inclusive. Use C4D strategies, which could be a strong enabler for creating mass awareness. Involve faith-based leaders and local leaders to sensitize communities on disabilities. |

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# PARENTING SUPPORT FOR CHILDREN WITH DEVELOPMENTAL DELAYS AND DISABILITIES

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for every child